PUBLIC HEARING

before

ASSEMBLY JUDICIARY, LAW AND PUBLIC SAFETY COMMITTEE

ASSEMBLY AND SENATE BILL NOS. A-16/S-1211, A-1191, A-1341, A-1413, A-2466, A-2467, A-2492, A-2514, A-2957, and S-1208

(Legislation Dealing with the Right to Die)

November 15, 1990
Room 418
State House Annex
Trenton, New Jersey

MEMBERS OF COMMITTEE PRESENT:

Assemblywoman Marlene Lynch Ford, Chairman
Assemblyman Frank M. Pelly, Vice-Chairman
Assemblyman Thomas J. Shusted
Assemblyman Gary W. Stuhltrager

ALSO PRESENT:

Assemblyman Gerard S. Naples
District 15

Patricia K. Nagle
Office of Legislative Services
Aide, Assembly Judiciary, Law
and Public Safety Committee

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Hearing Recorded and Transcibed by
Office of Legislative Services
Public Information Office
Hearing Unit
State House Annex
CN 068
Trenton, New Jersey 08625

MARLENE LYNCH FORD
CHAIRMAN
FRANK M. PELLY
VICE-CHAIRMAN
Joseph Charles, Jr.
THOMAS J. SHUSTED
GARY W. STUHLTRAGER

New Jersey State Legislature
ASSEMBLY JUDICIARY, LAW AND PUBLIC SAFETY COMMITTEE
STATE HOUSE ANNEX, CN-068
TRENTON, NEW JERSEY 08625-0068
(609) 292-5526

NOTICE OF PUBLIC HEARING

The Assembly Judiciary, Law and Public Safety Committee will hold a public hearing on **Thursday, November 15, 1990 at 11:00 a.m. in Room 418, State House Annex, Trenton.**

The hearing will be held on the following legislation:

A-16 Naples/Randall S-1211 Ambrosio	Designated the "New Jersey Advance Directives for Health Care Act."
A-1191 Cooper	"Death with Dignity Act"
A-1341 Bryant	The "Right to Die Act," concerns use of life sustaining medical treatment of terminally ill persons.
A-1413 Kamin/Schwartz	Enacts the "New Jersey Declaration of Death Act."
A-2466 Randall	The "Medical Power of Attorney and Treatment Decision Act," establishes a procedure through which an individual can control decisions regarding continuation of artificial life-support systems when suffering from a terminal condition.
A-2467 Randall	Provides for the withholding of life-sustaining treatment in the absence of a medical directive or power of attorney.
A-2492 Randall/Schuber	Establishes the New Jersey Health Care Directive Act.

(OVER)

Issued 11/5/90

A-2514 Randall/Naples	Designated the "New Jersey Advance Directives for Health Care Act."
A-2957 Kronick/Kenny/ Roma/Ogden	The "Natural Death Act."
S-1208 Ambrosio	Enacts the "New Jersey Declaration of Death Act."

Revised 11/5/90

The public may address comments and questions to Patricia K. Nagle, Committee Aide and persons wishing to testify should contact Miriam Torres or Helen Rouze, secretaries at (609) 292-5526. Those persons presenting written testimony should provide 10 copies to the committee on the day of the hearing.

ASSEMBLY, No. 16

STATE OF NEW JERSEY

Introduced Pending Technical Review by Legislative Counsel

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Assemblyman NAPLES

AN ACT concerning health care decision making.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. This act shall be known and may be cited as the "New Jersey Advance Directives for Health Care Act."

2. The Legislature finds and declares that:

a. Competent adults have the fundamental right, in collaboration with their health care providers, to control decisions about their own health care. This State recognizes, in its law and public policy, the personal right of the individual patient to make voluntary, informed choices to accept, to reject, or to choose among alternative courses of medical and surgical treatment.

b. Modern advances in science and medicine have made possible the prolongation of the lives of many seriously ill individuals, without always offering realistic prospects for improvement or cure. For some individuals the possibility of extended life is experienced as meaningful and of benefit. For others, artificial prolongation of life may seem to provide nothing medically necessary or beneficial, serving only to extend suffering and prolong the dying process. This State recognizes that the fundamental right of individual choice extends to decisions to have life-prolonging medical or surgical means or procedures provided, withheld, or withdrawn.

c. In order that the right to control decisions about one's own health care should not be lost in the event a patient loses decision making capacity and is no longer able to participate actively in making his own health care decisions, this State recognizes the right of competent adults to plan ahead for health care decisions through the execution of advance directives, such as living wills and durable powers of attorney, and to have the wishes expressed therein respected, subject to certain limitations.

d. The right of individuals to forego life-sustaining measures is subject to certain interests of society. The most significant of these societal interests is the preservation of life, understood to embrace both an interest in preserving the life of the particular patient and a related but distinct interest in preserving the sanctity of all human life as an enduring social value. A second, closely related societal interest is the protection of individuals from direct and purposeful self-destruction, motivated by a specific intent to die. A third interest is the protection of innocent third parties who may be harmed by the patient's decision to forego therapy; this interest may be asserted to prevent the emotional and financial abandonment of the patient's minor children or to protect the paramount concerns of public health or safety. A fourth interest encompasses safeguarding the ethical integrity of the health care professions, individual professionals, and health care institutions, and maintaining public confidence and trust in the integrity and caring role of health care professionals and institutions. Finally, society has an interest in ensuring the soundness of health care decision making, including both protecting vulnerable patients from potential abuse or neglect and facilitating the exercise of informed and voluntary patient choice.

e. In accordance with these State interests, this State expressly rejects on both legal and moral grounds the practice of active euthanasia, as by deliberate lethal injection intended to cause death. No individual shall have the right to, nor shall any physician or other health care professional be authorized to engage in, the practice of active euthanasia.

f. In order to assure respect for patients' previously expressed wishes when the capacity to participate actively in decision making has been lost or impaired; to facilitate and encourage a sound decision making process in which patients, health care representatives, families, physicians, and other health care professionals are active participants; to properly consider patients' interests both in self-determination and in well-being; and to provide necessary and appropriate safeguards concerning the termination of life-sustaining treatment for incompetent patients as the law and public policy of this State, the Legislature hereby enacts the New Jersey Advance Directives for Health Care Act.

3. As used in this act:

"Adult" means an individual 18 years of age or older.

"Advance directive for health care" or "advance directive" means a writing executed in accordance with the requirements of this act. An "advance directive" may include a proxy directive or an instruction directive, or both.

"Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

"Decision making capacity" means a patient's ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of each, and alternatives to any proposed health care, and to reach an informed decision. A patient's decision making capacity is evaluated relative to the demands of a particular health care decision.

"Declarant" means a competent adult who executes an advance directive.

"Do not resuscitate order" means a physician's written order not to attempt cardiopulmonary resuscitation in the event the patient suffers a cardiac or respiratory arrest.

"Emergency care" means immediate treatment provided in response to a sudden, acute and unanticipated medical crisis in order to avoid injury, impairment or death.

"Health care decision" means a decision to accept or to refuse any treatment, service or procedure used to diagnose, treat or care for a patient's physical or mental condition, including life-sustaining treatment. "Health care decision" also means a decision to accept or to refuse the services of a particular physician, nurse, other health care professional or health care institution, including a decision to accept or to refuse a transfer of care.

"Health care institution" means all institutions, facilities, and agencies licensed, certified, or otherwise authorized by State law to administer health care in the ordinary course of business, including hospitals, nursing homes, residential health care facilities, home health care agencies, and hospice programs operating in this State, but does not include mental health institutions, facilities or agencies, or institutions, facilities or agencies for the developmentally disabled. The term "health care institution" shall not be construed to include "health care professionals" as defined in this act.

"Health care professional" means an individual licensed by this State to administer health care in the ordinary course of business or practice of a profession.

"Health care representative" means the individual designated by a declarant pursuant to the proxy directive part of an advance directive for the purpose of making health care decisions on the declarant's behalf, and includes an individual designated as an alternate health care representative who is acting as the declarant's health care representative in accordance with the terms and order of priority stated in an advance directive.

"Instruction directive" means a writing which may be a component of an advance directive and which provides instructions and direction regarding the declarant's wishes for health care in the event that the declarant lacks decision making capacity. An "instruction directive" may be referred to as a living will.

"Life-sustaining treatment" means the use of any medical device or procedure, drugs, surgery or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function, and thereby increase the expected life span of a patient.

"Other health care professionals" means health care professionals other than physicians and nurses.

"Patient" means an individual who is under the care of a physician, nurse or other health care professional.

"Permanently unconscious" means a medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term "permanently unconscious" includes without limitation a persistent vegetative state or irreversible coma.

"Physician" means an individual licensed to practice medicine and surgery in this State.

"Proxy directive" means a writing which may be a component of an advance directive and which designates a health care representative in the event the declarant lacks decision making capacity. A "proxy directive" may be referred to as a medical durable power of attorney.

"State" means a state, territory, or possession of the United States, the District of Columbia, or the Commonwealth of Puerto Rico.

"Terminal condition" means the terminal stage of an irreversibly fatal illness, disease or condition. A determination of a specific life expectancy is not required as a precondition for a diagnosis of a "terminal condition," but a prognosis of a life expectancy of six months or less, with or without the provision of life-sustaining treatment, based upon reasonable medical certainty, shall be deemed to constitute a terminal condition.

4. A declarant may execute an advance directive for health care at any time. The advance directive shall be signed and dated by, or at the direction of, the declarant in the presence of two subscribing adult witnesses, who shall attest that the declarant is of sound mind and free of duress and undue influence. A designated health care representative shall not act as a witness to the execution of an advance directive. An advance directive may be supplemented by a video or audio tape recording.

An advance directive may be made self-proved at the time of execution by following the formal requirements stated in N.J.S.3B:3-4 for making a testamentary will self-proved.

5. a. A declarant may reaffirm or modify either a proxy directive, or an instruction directive, or both. The reaffirmation or modification shall be made in accordance with the requirements for execution of an advance directive pursuant to section 4 of this act.

b. A declarant, whether competent or incompetent, may revoke a prior proxy directive, or a prior instruction directive, or both, by the following means:

(1) Notification, orally or in writing, to the health care

representative, attending physician, nurse or other health care professional, or other reliable witness;

(2) Destruction or attempted destruction of the document, or other act evidencing an intent to revoke the document; or

(3) Execution of a subsequent proxy directive or instruction directive, or both, in accordance with section 4 of this act.

c. Designation of the declarant's spouse as health care representative shall be revoked upon divorce or legal separation, unless otherwise specified in the advance directive.

d. Reaffirmation, modification or revocation of an advance directive is effective upon communication to the health care representative, the attending physician, nurse or other health care professional responsible for the patient's care.

6. a. A declarant may execute a proxy directive, pursuant to the requirements of section 4 of this act, designating a competent adult to act as his health care representative.

(1) A competent adult, including, but not limited to, a declarant's spouse, adult child, parent or other family member, friend, religious or spiritual advisor, or other person of the declarant's choosing, may be designated as a health care representative.

(2) A declarant may not designate as a health care representative an operator, administrator or employee of a health care institution in which, at the time the advance directive is executed, the declarant is a patient or resident, or has applied for admission, unless the operator, administrator or employee is related to the declarant by blood, marriage or adoption.

This restriction does not apply to a physician, if the physician does not serve as the patient's attending physician and the patient's health care representative at the same time.

(3) A declarant may designate one or more alternate health care representatives, listed in order of priority. In the event the primary designee is unavailable, unable or unwilling to serve as health care representative, or is disqualified from such service pursuant to this section or any other law, the next designated alternate shall serve as health care representative. In the event the primary designee subsequently becomes available and able to serve as health care representative, the primary designee may, insofar as then practicable, serve as health care representative.

(4) A declarant may direct the health care representative to consult with specified individuals, including alternate designees, family members and friends, in the course of the decision making process.

(5) A declarant shall state the limitations, if any, to be placed upon the authority of the health care representative.

b. A declarant may execute an instruction directive, pursuant to the requirements of section 4 of this act, stating the declarant's general treatment philosophy and objectives; or the

declarant's specific wishes regarding the provision, withholding or withdrawal of any form of health care, including life-sustaining treatment; or both. An instruction directive may, but need not, be executed contemporaneously with, or be attached to, a proxy directive.

A declarant who chooses to instruct that artificially provided fluids and nutrition should be withheld or withdrawn under certain conditions shall so indicate by an explicit statement in the instruction directive.

7. a. An advance directive becomes operative when (1) it is transmitted to the attending physician or to the health care institution, and (2) it is determined pursuant to section 8 of this act that the patient lacks decision making capacity.

b. Treatment decisions pursuant to an advance directive shall not be made and implemented until there has been an reasonable opportunity to establish, and where appropriate confirm, a reliable diagnosis and prognosis for the patient.

8. a. The attending physician shall determine whether the patient lacks decision making capacity. The determination shall be stated in writing, shall include the attending physician's opinion concerning the nature, cause, extent, and probable duration of the patient's incapacity, and shall be made a part of the patient's medical records.

b. The attending physician's determination of a lack of decision making capacity shall be confirmed by one or more physicians. The opinion of the confirming physician shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician. Confirmation of a lack of decision making capacity is not required when the patient's lack of decision making capacity is clearly apparent, and the attending physician and the health care representative agree that confirmation is unnecessary.

c. If the attending physician or the confirming physician determines that a patient lacks decision making capacity because of a mental or psychological impairment or a developmental disability, and neither the attending physician or the confirming physician has specialized training or experience in diagnosing mental or psychological conditions or developmental disabilities of the same or similar nature, a determination of a lack of decision making capacity shall be confirmed by one or more physicians with appropriate specialized training or experience. The opinion of the confirming physician shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician.

d. A physician designated by the patient's advance directive as a health care representative shall not serve as the confirming physician for the determination of a lack of decision making capacity.

e. The attending physician shall inform the patient, if the patient has any ability to comprehend that he has been determined to lack decision making capacity, and the health care representative that: (1) the patient has been determined to lack decision making capacity to make a particular health care decision; (2) each has the right to contest this determination; and (3) each may have recourse to the dispute resolution process established by the health care institution pursuant to section 14 of this act.

Notice to the patient and the health care representative shall be documented in the patient's medical records.

f. A determination of lack of decision making capacity under this act is solely for the purpose of implementing an advance directive in accordance with the provisions of this act, and shall not be construed as a determination of a patient's incapacity or incompetence for any other purpose.

g. For purposes of this section, a determination that a patient lacks decision making capacity shall be based upon, but need not be limited to, evaluation of the patient's ability to understand and appreciate the nature and consequences of a particular health care decision, including the benefits and risks of, and alternatives to, the proposed health care, and to reach an informed decision.

9. a. A health care representative shall have legal authority to make health care decisions on behalf of the patient. The health care representative shall act in good faith and within the bounds of the authority granted by the advance directive and by this act.

b. If a different individual has been appointed as the patient's legal guardian, the health care representative shall retain legal authority to make health care decisions on the patient's behalf, unless the terms of the legal guardian's court appointment or other court decree provide otherwise.

c. The conferral of legal authority on the health care representative shall not be construed to impose liability upon the health care representative for any portion of the patient's health care costs.

d. An individual designated as a health care representative or as an alternate health care representative may decline to serve in that capacity.

e. The health care representative shall exercise the patient's right to be informed of the patient's medical condition, prognosis and treatment options, and to give informed consent to, or refusal of, health care.

10. In addition to any rights and responsibilities recognized or imposed by, or pursuant to, this act, or by any other law, physicians, nurses, and other health care professionals shall have the following rights and responsibilities:

a. The attending physician shall make an affirmative inquiry of the patient, his family or others, as appropriate under the circumstances, concerning the existence of an advance directive. The attending physician shall note in the patient's medical records whether or not an advance directive exists, and the name of the patient's health care representative, if any, and shall attach a copy of the advance directive to the patient's medical records. The attending physician shall document in the same manner the reaffirmation, modification, or revocation of an advance directive, if he has knowledge of such action.

b. A physician may decline to participate in the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life, in accordance with his sincerely held personal or professional convictions. In such circumstances, the physician shall act in good faith to inform the patient and the health care representative, and the chief of the medical staff or other designated institutional official, of this decision as soon as practicable, to effect an appropriate, respectful and timely transfer of care, and to assure that the patient is not abandoned or treated disrespectfully.

In the event of transfer of a patient's care, the attending physician shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

c. A nurse or other health care professional may decline to participate in the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life, in accordance with his sincerely held personal or professional convictions. In these circumstances, the nurse and other health care professional shall act in good faith to inform the patient and the health care representative, and the head of the nursing or other professional staff or other designated institutional official, of this decision as soon as practicable, to cooperate in effecting an appropriate, respectful and timely transfer of care, and to assure that the patient is not abandoned or treated disrespectfully.

d. Nothing in this act shall be construed to require a physician, nurse or other health care professional to begin, continue, withhold, or withdraw health care in a manner contrary to law or accepted professional standards.

11. a. The attending physician, the health care representative and, when appropriate, any additional physician responsible for the patient's care, shall discuss the nature and consequences of the patient's medical condition, and the risks, benefits and burdens of the proposed health care and its alternatives. Except as provided by subsection b. of this section, the attending physician shall obtain informed consent for, or refusal of, health care from the health care representative.

(1) Discussion of the proposed treatment and its alternatives

shall include, as appropriate under the circumstances, the availability, benefits and burdens of rehabilitative treatment, therapy, and services.

(2) The decision making process shall allow, as appropriate under the circumstances, adequate time for the health care representative to understand and deliberate about all relevant information before a treatment decision is implemented.

b. Following a determination that a patient lacks decision making capacity, the health care representative and the attending physician shall, to a reasonable extent, discuss the treatment options with the patient, and seek to involve the patient as a participant in the decision making process. The health care representative and the attending physician shall seek to promote the patient's capacity for effective participation and shall take the patient's expressed wishes into account in the decision making process.

If the patient is found to possess adequate decision making capacity with respect to a particular health care decision, the patient shall retain legal authority to make that decision. In such circumstances, the health care representative may continue to participate in the decision making process in an advisory capacity, unless the patient objects.

Notwithstanding any other provision of this act to the contrary, if a patient who lacks decision making capacity clearly expresses or manifests the contemporaneous wish that medically appropriate life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life be provided, that wish shall take precedence over any contrary decision of the health care representative and any contrary statement in the patient's instruction directive.

c. In acting to implement a patient's wishes pursuant to an advance directive, the health care representative shall give priority to the patient's instruction directive, and may also consider, as appropriate and necessary, the following forms of evidence of the patient's wishes:

(1) Reliable oral or written statements previously made by the patient, including, but not limited to, statements made to family members, friends, health care professionals or religious leaders;

(2) Other reliable sources of information, including the health care representative's personal knowledge of the patient's values, preferences and goals; and

(3) The patient's contemporaneous expressions, including nonverbal expressions.

d. If the instruction directive, in conjunction with other evidence of the patient's wishes, does not provide, in the exercise of reasonable judgment, clear direction as applied to the patient's medical condition and the treatment alternatives, the health care representative shall exercise reasonable discretion, in good faith, to effectuate the terms, intent, and spirit of the instruction directive and other evidence of the patient's wishes.

e. If the patient's wishes cannot be adequately determined, then the health care representative shall make a health care decision in the patient's best interests.

12. a. If the patient has executed an instruction directive but has not designated a health care representative, or if neither the designated health care representative or any alternate designee is able or available to serve, the instruction directive shall be legally operative. If the instruction directive provides clear and unambiguous guidance under the circumstances, it shall be honored in accordance with its specific terms by a legally appointed guardian, if any, family members, the attending physician, nurses, other health care professionals, health care institutions, and others acting on the patient's behalf.

b. If the instruction directive is, in the exercise of reasonable judgment, not specific to the patient's medical condition and the treatment alternatives, the attending physician, in consultation with a legally appointed guardian, if any, family members, or others acting on the patient's behalf, shall exercise reasonable judgment to effectuate the wishes of the patient, giving full weight to the terms, intent, and spirit of the instruction directive. Departure from the specific terms and provisions of the instruction directive shall be based upon clearly articulate factors not foreseen or contemplated by the instruction directive, including, but not limited to, the circumstances of the patient's medical condition.

c. Nothing in this act shall be construed to impair the legal force and effect of an instruction directive executed prior to the effective date of this act.

13. a. In addition to any rights and responsibilities recognized or imposed by, or pursuant to, this act, or any other law, a health care institution shall have the following rights and responsibilities:

(1) A health care institution shall adopt such policies and practices as are necessary to provide for routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive.

(2) A health care institution shall adopt such policies and practices as are necessary to provide appropriate informational materials concerning advance directives to all interested patients and their families and health care representatives, and to assist patients interested in discussing and executing an advance directive.

(3) A health care institution shall adopt such policies and practices as are necessary to educate patients and their families and health care representatives about the availability, benefits and burdens of rehabilitative treatment, therapy and services,

including but not limited to, family and social services, self-help and advocacy services, employment and community living, and use of assistive devices. A health care institution shall, in consultation with the attending physician, assure that such information is discussed with a patient and his health care representative and made a part of the decision making process set forth in section 11 of this act, as appropriate under the circumstances.

(4) In situations in which a transfer of care is necessary, including a transfer for the purpose of effectuating a patient's wishes regarding the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life, a health care institution shall, in consultation with the attending physician, take all reasonable steps to effect the appropriate, respectful and timely transfer of the patient to the care of an alternative health care professional or institution, as necessary, and shall assure that the patient is not abandoned or treated disrespectfully. In such circumstances, a health care institution shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

(5) A health care institution shall establish procedures and practices for dispute resolution, in accordance with section 14 of this act.

(6) A health care institution shall adopt such policies and practices as are necessary to inform physicians, nurses and other health care professionals of their rights and responsibilities under this act, to assure that such rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this act.

b. A private, religiously-affiliated health care institution may develop institutional policies and practices defining circumstances in which it will decline to participate in the withholding or withdrawing of specified life-sustaining treatments or artificially provided fluids and nutrition necessary to sustain life. Such policies and practices shall be written, and shall be properly communicated to patients and their families and health care representatives prior to or upon the patient's admission, or as soon after admission as is practicable.

If the institutional policies and practices appear to conflict with the legal rights of a patient wishing to forego health care, the health care institution shall attempt to resolve the conflict, and if a mutually satisfactory accommodation cannot be reached, shall take all reasonable steps to effect the appropriate, timely and respectful transfer of the patient to the care of another health care institution appropriate to the patient's needs, and shall assure that the patient is not abandoned or treated disrespectfully.

c. Nothing in this act shall be construed to require a health care institution to participate in the beginning, continuing, withholding or withdrawing of health care in a manner contrary to law or accepted medical standards.

14. a. In the event of disagreement among the patient, health care representative and attending physician concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive to the patient's course of treatment, the parties shall seek to resolve the disagreement by means of procedures and practices established by the health care institution, including but not limited to, consultation with an institutional ethics committee, or with a person designated by the health care institution for this purpose.

b. A health care professional involved in the patient's care, other than the attending physician, or an administrator of a health care institution may also invoke the dispute resolution process established by the health care institution to seek to resolve a disagreement concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive.

c. If disagreement cannot be reconciled through an institutional dispute resolution process, the parties may seek resolution in a court of competent jurisdiction.

15. a. Consistent with the terms of an advance directive and the provisions of this act, life-sustaining treatment, other than artificially provided fluids and nutrition necessary to sustain life, may be withheld or withdrawn from a patient in the following circumstances:

(1) When the life-sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician;

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician; or

(4) In the event none of the above circumstances applies, when the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the medical intervention to be withheld or withdrawn may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the medical intervention on an unwilling patient would be inhumane. In such cases prior to implementing a decision to withhold or withdraw life-sustaining treatment, the attending physician shall promptly seek

consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this act, or shall promptly seek approval of a public agency recognized by law for this purpose.

b. Nothing in this section shall be construed to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

c. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

16. a. Consistent with the explicit terms of an advance directive and the provisions of this act, artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient in the following circumstances:

(1) When the artificial provision of fluids and nutrition is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician; or

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician, and the likely risks and burdens associated with the least burdensome treatment modality likely to be effective may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the intervention on an unwilling patient would be inhumane. In such cases, prior to implementing a decision to withhold or withdraw artificially provided fluids and nutrition, the attending physician shall seek prompt consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this act, or shall promptly seek approval of a public agency recognized by law for this purpose.

b. Nothing in this section shall be construed to provide authorization for the health care representative, or any other individual acting pursuant to this act, to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to sustain life in the absence of explicit instructions to that effect in the patient's advance directive.

c. Nothing in this section shall be construed to impair the obligations of a physician, nurse or other health care professional to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

d. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

17. a. Consistent with the terms of an advance directive and the provisions of this act, the attending physician may issue a do not resuscitate order.

b. A do not resuscitate order shall be entered in writing in the patient's medical records prior to implementation of the order.

c. Nothing in this act shall be construed to impair any existing legal authority to issue a do not resuscitate order when the patient has not executed an advance directive.

18. a. An institutional or regional reviewing body which engages in prospective case consultation pursuant to paragraph (4) of subsection a. of section 15 and paragraph (3) of subsection a. of section 16 of this act shall advise the attending physician, patient and health care representative whether it believes that the withholding or withdrawal of the medical intervention under consideration would be in conformity with the requirements of this act, including without limitation: whether such action would be within the scope of the patient's advance directive; whether it may reasonably be judged that the likely risks and burdens associated with the medical intervention to be withheld or withdrawn outweigh its likely benefits; and whether it may reasonably be judged that imposition of the medical intervention on an unwilling patient would be inhumane. The attending physician, patient and health care representative shall also be advised of any other course of diagnosis or treatment recommended for consideration.

The advice of the institutional or regional reviewing body shall be documented in the patient's medical records.

b. The advice of an institutional or regional reviewing body acting in accordance with subsection a. of this section is not legally binding. A health care representative, attending physician, nurse, or other health care professional who believes the advice should not be followed may choose to:

(1) Pursue an alternative course of treatment for the patient. In this case, no immunity is conferred upon such actions by this act, and the individual is subject to civil and criminal liability and may be subject to discipline by the respective State licensing board for professional misconduct;

(2) Seek review by a public agency recognized by law for this purpose; or

(3) Seek review by a court of competent jurisdiction.

c. Nothing in this section shall preclude the transfer of the patient to another appropriate health care professional or health care institution. In this case the health care institution responsible for the patient's care shall assure that the health care professional or health care institution to which the patient is transferred is properly informed of the advice given by the institutional or regional reviewing body.

d. An institutional or regional reviewing body acting in accordance with subsection a. of this section shall conform to standards established by law and shall be subject to periodic accreditation and review under procedures established by law.

19. a. Nothing in this act shall be construed to alter, amend or revoke the rights and responsibilities under existing law of health care institutions not governed by the provisions of this act.

b. Nothing in this act shall be construed to preclude mental health institutions, facilities or agencies, or institutions, facilities or agencies for the developmentally disabled, from respecting an advance directive for health care executed by a patient or resident pursuant to this act.

c. The provisions of this act shall not be construed to require emergency personnel, including paid or volunteer fire fighters; paramedics; members of an ambulance team, rescue squad, or mobile intensive care unit; or emergency room personnel of a licensed health care institution, to withhold or withdraw emergency care in circumstances which do not afford reasonable opportunity for careful review and evaluation of an advance directive without endangering the life of the patient.

20. In accordance with the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.) the Department of Health shall establish rules and regulations necessary to carry out the provisions of this act. The rules and regulations shall require a health care institution to adopt policies and practices designed to:

a. Make routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive;

b. Provide appropriate informational materials concerning advance directives to all interested patients and their families and health care representatives, and to assist patients interested in discussing and executing an advance directive;

c. Educate patients and their families and health care representatives about the availability, benefits and burdens of rehabilitative treatment, therapy and services, as appropriate;

d. In cooperation with the respective State licensing boards, inform physicians, nurses, and other health care professionals of their rights and responsibilities under this act, to assure that the rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this act; and

e. Otherwise comply with the provisions of this act, including procedures for reporting to the department by health care institutions, and the gathering of such additional data as is reasonably necessary to oversee and evaluate the implementation of this act. The Department of Health shall seek to minimize the burdens of record-keeping imposed by the rules and regulations and shall seek to assure the appropriate confidentiality of patient records.

21. The Department of Health and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care established pursuant to P.L.1985, c.363 (C.52:9Y-1 et seq.), shall jointly evaluate the implementation of this act and report to the Governor and the Legislature, including recommendations for any changes deemed necessary, within five years from the effective date of this act.

22. a. A health care representative shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act:

(1) To carry out the terms of an advance directive; or

(2) To follow and implement the advice of an institutional or regional reviewing body acting in accordance with subsection a. of section 18 of this act.

b. A health care professional shall not be subject to criminal or civil liability or to discipline by the health care institution or the respective State licensing board for professional misconduct for any actions performed in good faith and in accordance with the provisions of this act and accepted professional standards:

(1) To carry out the terms of an advance directive; or

(2) To follow and implement the advice of an institutional or regional reviewing body acting in accordance with subsection a. of section 18 of this act.

c. A health care institution shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act to carry out the terms of an advance directive.

23. The absence of an advance directive shall create no presumption with respect to a patient's wishes regarding the provision, withholding or withdrawing of any form of health care. The provisions of this act do not apply to persons who have not executed an advance directive.

24. The execution of an advance directive pursuant to this act shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual because that individual has executed or has not executed an advance directive. The execution, or non-execution, of an advance directive shall not be made a condition of coverage under any policy of health insurance, life

insurance or annuity, or governmental benefits program.

25. An advance directive executed in another state in compliance with the laws of that state or the State of New Jersey is validly executed for purposes of this act. An advance directive executed in a foreign country in compliance with the laws of that country or the State of New Jersey, and not contrary to the public policy of this State, is validly executed for purposes of this act.

26. a. The withholding or withdrawing of life-sustaining treatment pursuant to section 15 of this act or of artificially provided fluids and nutrition necessary to sustain life pursuant to section 16 of this act, when performed in good faith, and in accordance with the terms of an advance directive and the provisions of this act, shall not constitute homicide, suicide, assisted suicide, or active euthanasia.

b. To the extent any of the provisions of this act are inconsistent with P.L.1971, c.373 (C.46:2B-8 et seq.) concerning the designation of a health care representative, the provisions of this act shall supersede those of P.L.1971, c.373 (C.46:2B-8 et seq.).

Durable powers of attorney for health care executed pursuant to P.L.1971, c.373 (C.46:2B-8 et seq.) prior to the effective date of this act shall have the same legal force and effect as if they had been executed in accordance with the provisions of this act.

c. Nothing in this act shall be construed to impair the rights of emancipated minors under existing law.

27. The Office of the Ombudsman for the Institutionalized Elderly shall adopt policies and practices necessary to comply with the requirements of P.L......, c....... (C........)(now pending before the Legislature as this bill), and shall make a written statement of its obligations under that act available to the public.

28. The Office of the Public Guardian for Elderly Adults shall adopt policies and practices necessary to comply with the requirements of P.L........, c........ (C...........)(now pending before the Legislature as this bill), and shall make a written statement of its obligations under that act available to the public.

29. a. A health care professional who willfully fails to act in accordance with practices and procedures established by this act is subject to discipline for professional misconduct pursuant to P.L.1978, c.73 (C.45:1-21).

b. A health care institution that willfully fails to act in accordance with practices and procedures established by this act shall be subject to a fine of not more than $1,000 for each offense. For the purposes of this subsection, each violation shall constitute a separate offense. Penalties for violations of this act shall be recovered in a summary civil proceeding, brought in the name of the State in a court of competent jurisdiction pursuant to "the penalty enforcement law," N.J.S.2A:58-1 et seq.

c. The following acts constitute crimes:

(1) To willfully conceal, cancel, deface, obliterate or withhold personal knowledge of an advance directive or a modification or revocation thereof, without the declarant's consent, is a crime of the fourth degree.

(2) To falsify or forge an advance directive or a modification or revocation thereof of another individual is a crime of the fourth degree.

(3) To coerce or fraudulently induce the execution of an advance directive or a modification or revocation thereof is a crime of the fourth degree.

(4) To require or prohibit the execution of an advance directive or a modification or revocation thereof as a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program, or as a condition of the provision of health care is a crime of the fourth degree.

d. The sanctions provided in this section shall not be construed to repeal any sanctions applicable under other law.

30. This act shall take effect 180 days after the date of enactment.

STATEMENT

This bill establishes procedures for the execution of advance directives for health care. According to the bill, advance directives for health care may encompass both the designation of a health care representative, known as a proxy directive and a statement of personal wishes regarding health care in the event of loss of decision making capacity, known as an instruction directive.

The purpose of this bill is to assure the respect for patients' previously expressed wishes when the capacity to participate actively in health care decision making has been lost or impaired. The bill establishes a procedure that facilitates and encourages a sound decision making process in which patients, their families and health care representatives, physicians, and other health care professionals are active participants. In addition, the bill provides the necessary and appropriate safeguards concerning the termination of life-sustaining treatment for incompetent patients.

The bill provides that:

(1) An advance directive becomes operative when it is transmitted to the attending physician or to the health care institution, and when the person is determined to lack decision making capacity.

(2) Once operative, the advance directive designating a health care representative confers upon that person the legal authority to participate in the decision making process and to make health

care decisions on the patient's behalf.

(3) In the absence of a designated health care representative an instruction directive, once operative, shall be respected and implemented.

(4) Life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient pursuant to an advance directive only in certain specified circumstances.

(5) An impaired patient's contemporaneously expressed wish that medically appropriate life sustaining treatment or artificially provided fluids and nutrition necessary to sustain life be provided shall take precedence over any contrary decision of the health care representative and any contrary statement in the patient's instruction directive.

(6) A declarant's directive to withhold or withdraw artificially provided fluids and nutrition must be explicitly stated in an advance directive.

(7) Health care professionals may decline to participate in the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life on the basis of sincerely held personal or professional convictions. In such cases the health care professional shall facilitate the appropriate, respectful and timely transfer of the patient's care.

(8) Private, religiously-affiliated health care institutions may adopt institutional policies and practices defining circumstances in which they will decline to participate in the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life.

(9) Individuals and institutions acting in good faith and in accordance with the provisions of this act to carry out the terms of an advance directive shall be immune from legal liability and from discipline for unprofessional conduct.

This bill is the result of the work of the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care, established pursuant to P.L.1985, c.363 (C.52:9Y-1 et seq.). This commission was established by the Legislature in 1985 to provide a comprehensive and scholarly examination of the legal and ethical dilemmas in the delivery of health care posed by modern advances in science and medicine.

HEALTH

Designated the "New Jersey Advance Directives for Health Care Act."

SENATE, No. 1211

STATE OF NEW JERSEY

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Senator AMBROSIO

AN ACT concerning health care decision making and supplementing Title 26 and Title 52 of the Revised Statutes.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. This act shall be known and may be cited as the "New Jersey Advance Directives for Health Care Act."

2. The Legislature finds and declares that:

a. Competent adults have the fundamental right, in collaboration with their health care providers, to control decisions about their own health care. This State recognizes, in its law and public policy, the personal right of the individual patient to make voluntary, informed choices to accept, to reject, or to choose among alternative courses of medical and surgical treatment.

b. Modern advances in science and medicine have made possible the prolongation of the lives of many seriously ill individuals, without always offering realistic prospects for improvement or cure. For some individuals the possibility of extended life is experienced as meaningful and of benefit. For others, artificial prolongation of life may seem to provide nothing medically necessary or beneficial, serving only to extend suffering and prolong the dying process. This State recognizes the inherent dignity and value of human life and within this context recognizes the fundamental right of individuals to make health care decisions to have life-prolonging medical or surgical means or procedures provided, withheld, or withdrawn.

c. In order that the right to control decisions about one's own health care should not be lost in the event a patient loses decision making capacity and is no longer able to participate actively in making his own health care decisions, this State recognizes the right of competent adults to plan ahead for health care decisions through the execution of advance directives, such as living wills and durable powers of attorney, and to have the wishes expressed therein respected, subject to certain limitations.

d. The right of individuals to forego life-sustaining measures is not absolute and is subject to certain interests of society. The most significant of these societal interests is the preservation of life, understood to embrace both an interest in preserving the life of the particular patient and a related but distinct interest in preserving the sanctity of all human life as an enduring social value. A second, closely related societal interest is the protection of individuals from direct and purposeful self-destruction, motivated by a specific intent to die. A third interest is the protection of innocent third parties who may be harmed by the patient's decision to forego therapy; this interest may be asserted to prevent the emotional and financial abandonment of the patient's minor children or to protect the paramount concerns of public health or safety. A fourth interest encompasses safeguarding the ethical integrity of the health care professions, individual professionals, and health care institutions, and maintaining public confidence and trust in the integrity and caring role of health care professionals and institutions. Finally, society has an interest in ensuring the soundness of health care decision making, including both protecting vulnerable patients from potential abuse or neglect and facilitating the exercise of informed and voluntary patient choice.

e. In accordance with these State interests, this State expressly rejects on both legal and moral grounds the practice of active euthanasia. No individual shall have the right to, nor shall any physician or other health care professional be authorized to engage in, the practice of active euthanasia.

f. In order to assure respect for patients' previously expressed wishes when the capacity to participate actively in decision making has been lost or impaired; to facilitate and encourage a sound decision making process in which patients, health care representatives, families, physicians, and other health care professionals are active participants; to properly consider patients' interests both in self-determination and in well-being; and to provide necessary and appropriate safeguards concerning the termination of life-sustaining treatment for incompetent patients as the law and public policy of this State, the Legislature hereby enacts the New Jersey Advance Directives for Health Care Act.

3. As used in this act:

"Adult" means an individual 18 years of age or older.

"Advance directive for health care" or "advance directive" means a writing executed in accordance with the requirements of this act. An "advance directive" may include a proxy directive or an instruction directive, or both.

"Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

"Decision making capacity" means a patient's ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of each, and alternatives to any proposed health care, and to reach an informed decision. A patient's decision making capacity is evaluated relative to the demands of a particular health care decision.

"Declarant" means a competent adult who executes an advance directive.

"Do not resuscitate order" means a physician's written order not to attempt cardiopulmonary resuscitation in the event the patient suffers a cardiac or respiratory arrest.

"Emergency care" means immediate treatment provided in response to a sudden, acute and unanticipated medical crisis in order to avoid injury, impairment or death.

"Health care decision" means a decision to accept or to refuse any treatment, service or procedure used to diagnose, treat or care for a patient's physical or mental condition, including life-sustaining treatment. "Health care decision" also means a decision to accept or to refuse the services of a particular physician, nurse, other health care professional or health care institution, including a decision to accept or to refuse a transfer of care.

"Health care institution" means all institutions, facilities, and agencies licensed, certified, or otherwise authorized by State law to administer health care in the ordinary course of business, including hospitals, nursing homes, residential health care facilities, home health care agencies, hospice programs operating in this State, mental health institutions, facilities or agencies, or institutions, facilities and agencies for the developmentally disabled. The term "health care institution" shall not be construed to include "health care professionals" as defined in this act.

"Health care professional" means an individual licensed by this State to administer health care in the ordinary course of business or practice of a profession.

"Health care representative" means the individual designated by a declarant pursuant to the proxy directive part of an advance directive for the purpose of making health care decisions on the declarant's behalf, and includes an individual designated as an alternate health care representative who is acting as the declarant's health care representative in accordance with the terms and order of priority stated in an advance directive.

"Instruction directive" means a writing which provides instructions and direction regarding the declarant's wishes for health care in the event that the declarant subsequently lacks decision making capacity.

"Life-sustaining treatment" means the use of any medical device or procedure, drugs, surgery or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function, and thereby increase the expected life span of a patient.

"Other health care professionals" means health care professionals other than physicians and nurses.

"Patient" means an individual who is under the care of a physician, nurse or other health care professional.

"Permanently unconscious" means a medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term "permanently unconscious" includes without limitation a persistent vegetative state or irreversible coma.

"Physician" means an individual licensed to practice medicine and surgery in this State.

"Proxy directive" means a writing which designates a health care representative in the event the declarant subsequently lacks decision making capacity.

"State" means a state, territory, or possession of the United States, the District of Columbia, or the Commonwealth of Puerto Rico.

"Terminal condition" means the terminal stage of an irreversibly fatal illness, disease or condition. A determination of a specific life expectancy is not required as a precondition for a diagnosis of a "terminal condition," but a prognosis of a life expectancy of six months or less, with or without the provision of life-sustaining treatment, based upon reasonable medical certainty, shall be deemed to constitute a terminal condition.

4. A declarant may execute an advance directive for health care at any time. The advance directive shall be signed and dated by, or at the direction of, the declarant in the presence of two subscribing adult witnesses, who shall attest that the declarant is of sound mind and free of duress and undue influence. A designated health care representative shall not act as a witness to the execution of an advance directive. An advance directive may be supplemented by a video or audio tape recording.

5. a. A declarant may reaffirm or modify either a proxy directive, or an instruction directive, or both. The reaffirmation or modification shall be made in accordance with the requirements for execution of an advance directive pursuant to section 4 of this act.

b. A declarant may revoke an advance directive, including a proxy directive, or an instruction directive, or both, by the following means:

(1) Notification, orally or in writing, to the health care representative, physician, nurse or other health care professional, or other reliable witness, or by any other act evidencing an intent to revoke the document; or

(2) Execution of a subsequent proxy directive or instruction directive, or both, in accordance with section 4 of this act.

c. Designation of the declarant's spouse as health care representative shall be revoked upon divorce or legal separation, unless otherwise specified in the advance directive.

d. An incompetent patient may suspend an advance directive. including a proxy directive, an instruction directive, or both, by any of the means stated in paragraph (1) of subsection b. of this section. An incompetent patient who has suspended an advance directive may reinstate that advance directive by oral or written notification to the health care representative, physician, nurse or other health care professional of an intent to reinstate the advance directive.

e. Reaffirmation, modification, revocation or suspension of an advance directive is effective upon communication to any person capable of transmitting the information including the health care representative, the attending physician, nurse or other health care professional responsible for the patient's care.

6. a. A declarant may execute a proxy directive, pursuant to the requirements of section 4 of this act, designating a competent adult to act as his health care representative.

(1) A competent adult, including, but not limited to, a declarant's spouse, adult child, parent or other family member, friend, religious or spiritual advisor, or other person of the declarant's choosing, may be designated as a health care representative.

(2) An operator, administrator or employee of a health care institution in which the declarant is a patient or resident shall not serve as the declarant's health care representative unless the operator, administrator or employee is related to the declarant by blood, marriage or adoption.

This restriction does not apply to a physician, if the physician does not serve as the patient's attending physician and the patient's health care representative at the same time.

(3) A declarant may designate one or more alternate health care representatives, listed in order of priority. In the event the primary designee is unavailable, unable or unwilling to serve as health care representative, or is disqualified from such service pursuant to this section or any other law, the next designated alternate shall serve as health care representative. In the event the primary designee subsequently becomes available and able to serve as health care representative, the primary designee may, insofar as then practicable, serve as health care representative.

(4) A declarant may direct the health care representative to consult with specified individuals, including alternate designees, family members and friends, in the course of the decision making process.

(5) A declarant shall state the limitations, if any, to be placed upon the authority of the health care representative.

b. A declarant may execute an instruction directive, pursuant to the requirements of section 4 of this act, stating the declarant's general treatment philosophy and objectives; or the

declarant's specific wishes regarding the provision, withholding or withdrawal of any form of health care, including life-sustaining treatment; or both. An instruction directive may, but need not, be executed contemporaneously with, or be attached to, a proxy directive.

A declarant who chooses to instruct that artificially provided fluids and nutrition should be withheld or withdrawn under certain conditions shall so indicate by an explicit statement in the instruction directive.

7. a. An advance directive becomes operative when (1) it is transmitted to the attending physician or to the health care institution, and (2) it is determined pursuant to section 8 of this act that the patient lacks capacity to make a particular health care decision.

b. Treatment decisions pursuant to an advance directive shall not be made and implemented until there has been an reasonable opportunity to establish, and where appropriate confirm, a reliable diagnosis and prognosis for the patient.

8. a. The attending physician shall determine whether the patient lacks capacity to make a particular health care decision. The determination shall be stated in writing, shall include the attending physician's opinion concerning the nature, cause, extent, and probable duration of the patient's incapacity, and shall be made a part of the patient's medical records.

b. The attending physician's determination of a lack of decision making capacity shall be confirmed by one or more physicians. The opinion of the confirming physician shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician. Confirmation of a lack of decision making capacity is not required when the patient's lack of decision making capacity is clearly apparent, and the attending physician and the health care representative agree that confirmation is unnecessary.

c. If the attending physician or the confirming physician determines that a patient lacks decision making capacity because of a mental or psychological impairment or a developmental disability, and neither the attending physician or the confirming physician has specialized training or experience in diagnosing mental or psychological conditions or developmental disabilities of the same or similar nature, a determination of a lack of decision making capacity shall be confirmed by one or more physicians with appropriate specialized training or experience. The opinion of the confirming physician shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician.

d. A physician designated by the patient's advance directive as a health care representative shall not make or confirm the determination of a lack of decision making capacity.

e. The attending physician shall inform the patient, if the patient has any ability to comprehend that he has been determined to lack decision making capacity, and the health care representative that: (1) the patient has been determined to lack decision making capacity to make a particular health care decision; (2) each has the right to contest this determination; and (3) each may have recourse to the dispute resolution process established by the health care institution pursuant to section 14 of this act.

Notice to the patient and the health care representative shall be documented in the patient's medical records.

f. A determination of lack of decision making capacity under this act is solely for the purpose of implementing an advance directive in accordance with the provisions of this act, and shall not be construed as a determination of a patient's incapacity or incompetence for any other purpose.

g. For purposes of this section, a determination that a patient lacks decision making capacity shall be based upon, but need not be limited to, evaluation of the patient's ability to understand and appreciate the nature and consequences of a particular health care decision, including the benefits and risks of, and alternatives to, the proposed health care, and to reach an informed decision.

9. a. If it has been determined that the patient lacks decision making capacity, a health care representative shall have authority to make health care decisions on behalf of the patient. The health care representative shall act in good faith and within the bounds of the authority granted by the advance directive and by this act.

b. If a different individual has been appointed as the patient's legal guardian, the health care representative shall retain legal authority to make health care decisions on the patient's behalf, unless the terms of the legal guardian's court appointment or other court decree provide otherwise.

c. The conferral of legal authority on the health care representative shall not be construed to impose liability upon the health care representative for any portion of the patient's health care costs.

d. An individual designated as a health care representative or as an alternate health care representative may decline to serve in that capacity.

e. The health care representative shall exercise the patient's right to be informed of the patient's medical condition, prognosis and treatment options, and to give informed consent to, or refusal of, health care.

f. In the exercise of these rights and responsibilities, the health care representative shall seek to make the health care decision the patient would have made had he possessed decision making capacity under the circumstances, or, when the patient's wishes cannot adequately be determined, shall make a health care decision in the best interests of the patient.

10. In addition to any rights and responsibilities recognized or imposed by, or pursuant to, this act, or by any other law, physicians, nurses, and other health care professionals shall have the following rights and responsibilities:

a. The attending physician shall make an affirmative inquiry of the patient, his family or others, as appropriate under the circumstances, concerning the existence of an advance directive. The attending physician shall note in the patient's medical records whether or not an advance directive exists, and the name of the patient's health care representative, if any, and shall attach a copy of the advance directive to the patient's medical records. The attending physician shall document in the same manner the reaffirmation, modification, or revocation of an advance directive, if he has knowledge of such action.

b. A physician may decline to participate in the withholding or withdrawing of measures utilized to sustain life, in accordance with his sincerely held personal or professional convictions. In such circumstances, the physician shall act in good faith to inform the patient and the health care representative, and the chief of the medical staff or other designated institutional official, of this decision as soon as practicable, to effect an appropriate, respectful and timely transfer of care, and to assure that the patient is not abandoned or treated disrespectfully.

In the event of transfer of a patient's care, the attending physician shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

c. A nurse or other health care professional may decline to participate in the withholding or withdrawing of measures utilized to sustain life, in accordance with his sincerely held personal or professional convictions. In these circumstances, the nurse and other health care professional shall act in good faith to inform the patient and the health care representative, and the head of the nursing or other professional staff or other designated institutional official, of this decision as soon as practicable, to cooperate in effecting an appropriate, respectful and timely transfer of care, and to assure that the patient is not abandoned or treated disrespectfully.

d. Nothing in this act shall be construed to require a physician, nurse or other health care professional to begin, continue, withhold, or withdraw health care in a manner contrary to law or accepted professional standards.

11. a. The attending physician, the health care representative and, when appropriate, any additional physician responsible for the patient's care, shall discuss the nature and consequences of the patient's medical condition, and the risks, benefits and

burdens of the proposed health care and its alternatives. Except as provided by subsection b. of this section, the attending physician shall obtain informed consent for, or refusal of, health care from the health care representative.

(1) Discussion of the proposed treatment and its alternatives shall include, as appropriate under the circumstances, the availability, benefits and burdens of rehabilitative treatment, therapy, and services.

(2) The decision making process shall allow, as appropriate under the circumstances, adequate time for the health care representative to understand and deliberate about all relevant information before a treatment decision is implemented.

b. Following a determination that a patient lacks decision making capacity, the health care representative and the attending physician shall, to a reasonable extent, discuss the treatment options with the patient, and seek to involve the patient as a participant in the decision making process. The health care representative and the attending physician shall seek to promote the patient's capacity for effective participation and shall take the patient's expressed wishes into account in the decision making process.

Once decision making authority has been conferred upon a health care represenative pursuant to an advance directive, if the patient is subsequently found to possess adequate decision making capacity with respect to a particular health care decision, the patient shall retain legal authority to make that decision. In such circumstances, the health care representative may continue to participate in the decision making process in an advisory capacity, unless the patient objects.

Notwithstanding any other provision of this act to the contrary, if a patient who lacks decision making capacity clearly expresses or manifests the contemporaneous wish that medically appropriate measures utilized to sustain life be provided, that wish shall take precedence over any contrary decision of the health care representative and any contrary statement in the patient's instruction directive.

c. In acting to implement a patient's wishes pursuant to an advance directive, the health care representative shall give priority to the patient's instruction directive, and may also consider, as appropriate and necessary, the following forms of evidence of the patient's wishes:

(1) The patient's contemporaneous expressions, including nonverbal expressions;

(2) Other reliable sources of information, including the health care representative's personal knowledge of the patient's values, preferences and goals; and

(3) Reliable oral or written statements previously made by the patient, including, but not limited to, statements made to family

members, friends, health care professionals or religious leaders.

d. If the instruction directive, in conjunction with other evidence of the patient's wishes, does not provide, in the exercise of reasonable judgment, clear direction as applied to the patient's medical condition and the treatment alternatives, the health care representative shall exercise reasonable discretion, in good faith, to effectuate the terms, intent, and spirit of the instruction directive and other evidence of the patient's wishes.

e. Subject to the provisions of this act, and unless otherwise stated in the advance directive, if the patient's wishes cannot be adequately determined, then the health care representative shall make a health care decision in the patient's best interests.

12. a. If the patient has executed an instruction directive but has not designated a health care representative, or if neither the designated health care representative or any alternate designee is able or available to serve, the instruction directive shall be legally operative. If the instruction directive provides clear and unambiguous guidance under the circumstances, it shall be honored in accordance with its specific terms by a legally appointed guardian, if any, family members, the physicians, nurses, other health care professionals, health care institutions, and others acting on the patient's behalf.

b. If the instruction directive is, in the exercise of reasonable judgment, not specific to the patient's medical condition and the treatment alternatives, the attending physician, in consultation with a legally appointed guardian, if any, family members, or others acting on the patient's behalf, shall exercise reasonable judgment to effectuate the wishes of the patient, giving full weight to the terms, intent, and spirit of the instruction directive. Departure from the specific terms and provisions of the instruction directive shall be based upon clearly articulable factors not foreseen or contemplated by the instruction directive, including, but not limited to, the circumstances of the patient's medical condition.

c. Nothing in this act shall be construed to impair the legal force and effect of an instruction directive executed prior to the effective date of this act.

13. a. In addition to any rights and responsibilities recognized or imposed by, or pursuant to, this act, or any other law, a health care institution shall have the following rights and responsibilities:

(1) A health care institution shall adopt such policies and practices as are necessary to provide for routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive.

(2) A health care institution shall adopt such policies and practices as are necessary to provide appropriate informational materials concerning advance directives to all interested patients

and their families and health care representatives, and to assist patients interested in discussing and executing an advance directive.

(3) A health care institution shall adopt such policies and practices as are necessary to educate patients and their families and health care representatives about the availability, benefits and burdens of rehabilitative treatment, therapy and services, including but not limited to family and social services, self-help and advocacy services, employment and community living, and use of assistive devices. A health care institution shall, in consultation with the attending physician, assure that such information is discussed with a patient and his health care representative and made a part of the decision making process set forth in section 11 of this act, as appropriate under the circumstances.

(4) In situations in which a transfer of care is necessary, including a transfer for the purpose of effectuating a patient's wishes pursuant to an advance directive, a health care institution shall, in consultation with the attending physician, take all reasonable steps to effect the appropriate, respectful and timely transfer of the patient to the care of an alternative health care professional or institution, as necessary, and shall assure that the patient is not abandoned or treated disrespectfully. In such circumstances, a health care institution shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

(5) A health care institution shall establish procedures and practices for dispute resolution, in accordance with section 14 of this act.

(6) A health care institution shall adopt such policies and practices as are necessary to inform physicians, nurses and other health care professionals of their rights and responsibilities under this act, to assure that such rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this act.

b. A private, religiously-affiliated health care institution may develop institutional policies and practices defining circumstances in which it will decline to participate in the withholding or withdrawing of specified measures utilized to sustain life. Such policies and practices shall be written, and shall be properly communicated to patients and their families and health care representatives prior to or upon the patient's admission, or as soon after admission as is practicable.

If the institutional policies and practices appear to conflict with the legal rights of a patient wishing to forego health care, the health care institution shall attempt to resolve the conflict, and if a mutually satisfactory accommodation cannot be reached, shall take all reasonable steps to effect the appropriate, timely and respectful transfer of the patient to the care of another health care institution appropriate to the patient's needs, and shall assure that the patient is not abandoned or treated disrespectfully.

c. Nothing in this act shall be construed to require a health care institution to participate in the beginning, continuing, withholding or withdrawing of health care in a manner contrary to law or accepted medical standards.

14. a. In the event of disagreement among the patient, health care representative and attending physician concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive to the patient's course of treatment, the parties shall seek to resolve the disagreement by means of procedures and practices established by the health care institution, including but not limited to, consultation with an institutional ethics committee, or with a person designated by the health care institution for this purpose.

b. A health care professional involved in the patient's care, other than the attending physician, or an administrator of a health care institution may also invoke the dispute resolution process established by the health care institution to seek to resolve a disagreement concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive.

c. If disagreement cannot be reconciled through an institutional dispute resolution process, the parties may seek resolution in a court of competent jurisdiction.

15. a. Consistent with the terms of an advance directive and the provisions of this act, life-sustaining treatment, other than artificially provided fluids and nutrition necessary to sustain life, may be withheld or withdrawn from a patient in the following circumstances:

(1) When the life-sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician;

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician; or

(4) In the event none of the above circumstances applies, when the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the medical intervention to be withheld or withdrawn may reasonably be judged to outweigh the likely benefits to the patient from such

intervention, and imposition of the medical intervention on an unwilling patient would be inhumane. In such cases prior to implementing a decision to withhold or withdraw life-sustaining treatment, the attending physician shall promptly seek consultation with an institutional or regional reviewing body in accordance with section 18 of this act, or shall promptly seek approval of a public agency recognized by law for this purpose.

b. Nothing in this section shall be construed to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

c. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

16. a. Consistent with the explicit terms of an advance directive and the provisions of this act, artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient in the following circumstances:

(1) When the artificial provision of fluids and nutrition is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician; or

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician, and the likely risks and burdens associated with the least burdensome treatment modality likely to be effective may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the intervention on an unwilling patient would be inhumane. In such cases, prior to implementing a decision to withhold or withdraw artificially provided fluids and nutrition, the attending physician shall seek prompt consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this act, or shall promptly seek approval of a public agency recognized by law for this purpose.

b. Nothing in this act shall be construed to provide authorization for the health care representative, or any other individual acting pursuant to this act, to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to sustain life in the absence of explicit instructions to that effect in the patient's advance directive.

c. Nothing in this section shall be construed to impair the obligations of a physician, nurse or other health care professional to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

d. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

17. a. Consistent with the terms of an advance directive and the provisions of this act, the attending physician may issue a do not resuscitate order.

b. A do not resuscitate order shall be entered in writing in the patient's medical records prior to implementation of the order.

c. Nothing in this act shall be construed to impair any existing legal authority to issue a do not resuscitate order when the patient has not executed an advance directive.

18. a. An institutional or regional reviewing body which engages in prospective case consultation pursuant to paragraph (4) of subsection a. of section 15 and paragraph (3) of subsection a. of section 16 of this act shall advise the attending physician, patient and health care representative whether it believes that the withholding or withdrawal of the medical intervention under consideration would be in conformity with the requirements of this act, including without limitation: whether such action would be within the scope of the patient's advance directive; whether it may reasonably be judged that the likely risks and burdens associated with the medical intervention to be withheld or withdrawn outweigh its likely benefits; and whether it may reasonably be judged that imposition of the medical intervention on an unwilling patient would be inhumane. The attending physician, patient and health care representative shall also be advised of any other course of diagnosis or treatment recommended for consideration.

The advice of the institutional or regional reviewing body shall be documented in the patient's medical records.

b. The advice of an institutional or regional reviewing body acting in accordance with subsection a. of this section is not legally binding. A health care representative, physician, nurse, or other health care professional who believes the advice should not be followed may choose to:

(1) Pursue an alternative course of treatment for the patient. In this case, no immunity is conferred upon such actions by this act, and the individual is subject to existing norms of civil and criminal liability and may be subject to discipline by the respective State licensing board for professional misconduct;

(2) Seek review by a public agency recognized by law for this purpose; or

(3) Seek review by a court of competent jurisdiction.

c. Nothing in this section shall preclude the transfer of the patient to another appropriate health care professional or health care institution. In this case the health care institution responsible for the patient's care shall assure that the health care professional or health care institution to which the patient is transferred is properly informed of the advice given by the institutional or regional reviewing body.

d. An institutional or regional reviewing body acting in accordance with subsection a. of this section shall conform to standards established by law and shall be subject to periodic accreditation and review under procedures established by law.

19. a. Nothing in this act shall be construed to alter, amend or revoke the rights and responsibilities under existing law of health care institutions not governed by the provisions of this act.

b. The provisions of this act shall not be construed to require emergency personnel, including paid or volunteer fire fighters; paramedics; members of an ambulance team, rescue squad, or mobile intensive care unit; or emergency room personnel of a licensed health care institution, to withhold or withdraw emergency care in circumstances which do not afford reasonable opportunity for careful review and evaluation of an advance directive without endangering the life of the patient.

20. In accordance with the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.) the Department of Health shall establish rules and regulations necessary to carry out the provisions of this act.

a. The department shall establish rules and regulations for the annual reporting by health care institutions, and the gathering of such additional data as is reasonably necessary to oversee and evaluate the implementation of this act. The department shall seek to minimize the burdens of record-keeping imposed by the rules and regulations and shall seek to assure the appropriate confidentiality of patient records.

b. The department shall establish rules and regulations requiring health care institutions to adopt policies and practices designed to:

(1) Make routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive;

(2) Provide appropriate informational materials concerning advance directives to all interested patients and their families and health care representatives, and to assist patients interested in discussing and executing an advance directive;

(3) Educate patients and their families and health care representatives about the availability, benefits and burdens of rehabilitative treatment, therapy and services, as appropriate;

(4) Inform physicians, nurses, and other health care professionals of their rights and responsibilities under this act, to

assure that the rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this act; and

(5) Otherwise comply with the provisions of this act.

21. The Department of Health and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care established pursuant to P.L.1985, c.363 (C.52:9Y-1 et seq.), shall jointly evaluate the implementation of this act and report to the Governor and the Legislature, including recommendations for any changes deemed necessary, within five years from the effective date of this act.

22. a. A health care representative shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act:

(1) To carry out the terms of an advance directive; or

(2) To follow and implement the advice of an institutional or regional reviewing body acting in accordance with subsection a. of section 18 of this act.

b. A health care professional shall not be subject to criminal or civil liability or to discipline by the health care institution or the respective State licensing board for professional misconduct for any actions performed in good faith and in accordance with the provisions of this act, any rules and regulations established by the Department of Health pursuant to this act, and accepted professional standards:

(1) To carry out the terms of an advance directive; or

(2) To follow and implement the advice of an institutional or regional reviewing body acting in accordance with subsection a. of section 18 of this act.

c. A health care institution shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act to carry out the terms of an advance directive.

23. The absence of an advance directive shall create no presumption with respect to a patient's wishes regarding the provision, withholding or withdrawing of any form of health care. The provisions of this act do not apply to persons who have not executed an advance directive.

24. The execution of an advance directive pursuant to this act shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual because that individual has executed or has not executed an advance directive. The execution, or non-execution, of an advance directive shall not be made a

condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program.

25. An advance directive executed under the laws of another state in compliance with the laws of that state or the State of New Jersey is validly executed for purposes of this act. An advance directive executed in a foreign country in compliance with the laws of that country or the State of New Jersey, and not contrary to the public policy of this State, is validly executed for purposes of this act.

26. a. The withholding or withdrawing of life-sustaining treatment pursuant to section 15 of this act or of artificially provided fluids and nutrition necessary to sustain life pursuant to section 16 of this act, when performed in good faith, and in accordance with the terms of an advance directive and the provisions of this act, shall not constitute homicide, suicide, assisted suicide, or active euthanasia.

b. To the extent any of the provisions of this act are inconsistent with P.L.1971, c.373 (C.46:2B-8 et seq.) concerning the designation of a health care representative, the provisions of this act shall have priority over those of P.L.1971, c.373 (C.46:2B-8 et seq.).

Durable powers of attorney for health care executed pursuant to P.L.1971, c.373 (C.46:2B-8 et seq.) prior to the effective date of this act shall have the same legal force and effect as if they had been executed in accordance with the provisions of this act.

c. Nothing in this act shall be construed to impair the rights of emancipated minors under existing law.

27. The Office of the Ombudsman for the Institutionalized Elderly shall adopt regulations necessary to comply with the requirements of P.L.   , c.   (C.   ) (now pending before the Legislature as this bill), and shall make a written statement of its obligations under that act available to the public.

28. The Office of the Public Guardian for Elderly Adults shall adopt regulations necessary to comply with the requirements of P.L.   , c.   (C.   ) (now pending before the Legislature as this bill), and shall make a written statement of its obligations under that act available to the public.

29. a. A health care professional who willfully fails to act in accordance with the requirements of this act is subject to discipline for professional misconduct pursuant to section 8 of P.L.1978, c.73 (C.45:1-21).

b. A health care institution that willfully fails to act in accordance with the requirements of this act and regulations adopted in accordance with this act shall be subject to a fine of not more than $1,000 for each offense. For the purposes of this subsection, each violation shall constitute a separate offense. Penalties for violations of this act shall be recovered in a summary civil proceeding, brought in the name of the State in a court of competent jurisdiction pursuant to "the penalty enforcement law," N.J.S.2A:58-1 et seq.

c. The following acts constitute crimes:

(1) To willfully conceal, cancel, deface, obliterate or withhold personal knowledge of an advance directive or a modification or revocation thereof, without the declarant's consent, is a crime of the fourth degree.

(2) To falsify or forge an advance directive or a modification or revocation thereof of another individual is a crime of the fourth degree.

(3) To coerce or fraudulently induce the execution of an advance directive or a modification or revocation thereof is a crime of the fourth degree.

(4) To require or prohibit the execution of an advance directive or a modification or revocation thereof as a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program, or as a condition of the provision of health care is a crime of the fourth degree.

d. Commission of any of the acts identified in paragraphs (1), (2), or (3) of subsection c., resulting in the involuntary earlier death of a patient, shall constitute a crime of the fourth degree.

e. The sanctions provided in this section shall not be construed to repeal any sanctions applicable under other law.

30. This act shall take effect 180 days after the date of enactment.

JUDICIARY

Designated the "New Jersey Advance Directives for Health Care Act."

ASSEMBLY, No. 1191

STATE OF NEW JERSEY

Introduced Pending Technical Review by Legislative Counsel

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Assemblywoman COOPER

AN ACT permitting certain persons to execute documents directing discontinuance of maintenance medical treatment in the event of terminal illness.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. This act shall be known and may be cited as the "Death with Dignity Act."

2. The Legislature finds that adult persons have the fundamental right to control the decisions relating to the rendering of their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn in instances of a terminal condition.

In order that the rights of patients may be respected even after they are no longer able to participate actively in decisions about themselves, the Legislature hereby declares that the laws of this State shall recognize the right of an adult person to make a written declaration instructing his physician to withhold or withdraw life sustaining procedures in the event of a terminal condition.

3. As used in this act:

a. "Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

b. "Declaration" means a witnessed document in writing, voluntarily executed by the declarant in accordance with the requirements of this act.

c. "Life-sustaining procedure" means any medical procedure or intervention which, when applied to a qualified patient, would serve only to prolong the dying process and where, in the judgment of the attending physician, death will occur whether or not the procedures are utilized. "Life-sustaining procedure" shall not include the administration of medification or the performance of any medical procedure deemed necessary to provide comfort care.

d. "Qualified patient" means a patient who has executed a declaration in accordance with this act and who has been diagnosed and certified in writing to be afflicted with a terminal condition by two physicians who have personally examined the patient, one of whom shall be the attending physician.

4. a. Any person of sound mind and 18 years of age or older,

him or her to be of sound mind.

Witness..

Witness..

b. A declaration may include other specific directions. Should any of the other specific directions be held to be invalid, the invalidity shall not affect other directions of the declaration which can be given effect without the invalid direction, and to this end the directions in the declaration are severable.

6. A declaration may be revoked at any time by the declarant, without regard to his or her mental state or competency, by any of the following methods:

a. By being canceled, defaced, obliterated, or burnt, torn or otherwise destroyed by the declarant or by some person in his or her presence and by his or her direction.

b. By a written revocation of the declarant expressing his or her intent to revoke, signed and dated by the declarant. The attending physician shall record in the patient's medical record the time and date when he or she received notification of the written revocation.

c. By a verbal expression by the declarant of his or her intent to revoke the declaration. The revocation shall become effective upon communication to the attending physician by the declarant or by a person who is reasonably believed to be acting on behalf of the declarant. The attending physician shall record in the patient's medical record the time, date and place of the revocation and the time, date and place, if different, of when he or she received notification of the revocation.

7. a. An attending physician who has been notified of the existence of a declaration executed under this act shall, without delay after the diagnosis of a terminal condition of the declarant, take the necessary steps to provide for written certification and confirmation of the declarant's terminal condition, so that declarant may be deemed to be a qualified patient.

b. An attending physician who fails to comply with this section shall be deemed to have refused to comply with the declaration and shall be liable as specified in section 9 of this act.

8. a. The desires of a qualified patient who is competent shall at all times supersede the effect of the declaration.

b. If the qualified patient is incompetent at the time of the decision to withhold or withdraw life-sustaining procedures, a declaration executed in accordance with this act is presumed to be valid. For the purpose of this act, a physician or health care facility may presume in the absence of actual notice to the contrary that an individual who executed a declaration was of sound mind when it was executed. The fact of an individual's having executed a declaration shall not be considered as an declaration as a condition for being insured for, or receiving, health care services.

13. Nothing in this act shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In this respect the provisions of this act are cumulative.

14. This act shall create no presumption concerning the intention of an individual who has not executed a declaration to consent to the use or withholding of life-sustaining procedures in the event of a terminal condition.

15. This act shall take effect immediately.

STATEMENT

Death with dignity is to be a personal decision if humanly possible. This bill permits a person of sound mind, 18 years of age or older, to legally direct that in the event of a terminal illness no maintenance medical treatment is to be used to prolong his or her life.

JUDICIARY

"Death with Dignity Act."

ASSEMBLY, No. 1341

STATE OF NEW JERSEY

Introduced Pending Technical Review by Legislative Counsel

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Assemblyman BRYANT

AN ACT concerning the life-sustaining medical treatment of terminally ill persons and supplementing Title 26 of the Revised Statutes.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. This act shall be known and may be cited as the "Right to Die Act."

2. As used in this act:

a. "Attending physician" means the physician selected by, or assigned to, the terminally ill person and who has primary responsibility for the treatment and care of that person;

b. "Life-sustaining medical treatment" means any medical procedure which utilizes mechanical or other artificial means to sustain, restore or supplant a vital human bodily function and which is designed solely to postpone the moment of death, when death is imminent whether or not the procedures are utilized;

c. "Minor" means a person under 18 years of age;

d. "Physician" means a physician or surgeon licensed to practice medicine or surgery under chapter 9 of Title 45 of the Revised Statutes.

e. "Terminal illness" means an incurable condition caused by injury, disease or illness which, within reasonable medical judgment, will ultimately produce death and the application of life-sustaining procedures serve only to postpone the moment of death.

3. A person 18 years of age or older may execute a right to die document directing that if the person is ever certified to be suffering from a terminal illness, life-sustaining medical treatment shall not be administered to prolong that person's life. The document shall be executed to meet the requirements of a valid will as provided in chapter 3 of Title 3B of the New Jersey Statutes.

4. a. If a minor has been certified as terminally ill, the following person may execute the right to die document on behalf of the minor:

(1) the spouse of the terminally ill minor, if the spouse is not a minor; or

(2) the parent or guardian of the terminally ill minor.

b. A person named in paragraphs (1) or (2) of subsection a. of this section may not execute a document:

or that the physician had actual notice of a revocation and failed to act upon that revocation.

b. A health care facility or its employees shall be immune from civil or criminal liability when acting in reasonable reliance on and in compliance with a right to die document.

8. a. The withholding or withdrawal of life-sustaining medical treatment from a terminally ill person in accordance with the provisions of this act shall not, for any purpose, constitute a suicide.

b. The execution of a right to die document shall not restrict, inhibit or impair the sale, procurement or issuance of a policy of life insurance, nor shall it modify the terms of an existing life insurance policy. A life insurance policy shall not be legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining medical treatment in compliance with a right to die document, regardless of a term in the policy to the contrary.

c. A physician, health care facility, health care service plan, insurer issuing disability insurance, self-insured employee benefit plan or nonprofit hospital service plan shall not require a person to execute a right to die document as a condition for being insured for, or receiving, health care service.

9. This act shall not impair or supercede a legal right or legal responsibility which a person may have to effect the withholding or withdrawal of life-sustaining medical treatment in a lawful manner. In this respect, the provisions of this act are cumulative.

10. a. A person who knowingly and willfully conceals, destroys, falsifies or forges a document with intent to create the false impression that another person has directed that no life-sustaining medical treatment be administered or a person who knowingly and willfully conceals evidence of revocation of a right to die document is guilty of a crime of the first degree.

b. A person who knowingly and willfully conceals, destroys, falsifies or forges a document with intent to create the false impression that another person has not executed a right to die document is guilty of a crime of the third degree.

c. A person who executes a right to die document for the benefit of a terminally ill minor when the person has actual notice of indications made by that minor opposing the withholding or withdrawal of life-sustaining medical treatment or actual notice of opposition to the document by a parent guardian or spouse of the minor is guilty of a crime of the second degree.

11. This act shall take effect immediately.

ASSEMBLY, No. 1413

STATE OF NEW JERSEY

Introduced Pending Technical Review by Legislative Counsel

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Assemblymen KAMIN and SCHWARTZ

AN ACT concerning the determination of death, enacting the New Jersey Declaration of Death Act and supplementing Title 26 of the Revised Statutes.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. a. This act shall be known and may be cited as the "New Jersey Declaration of Death Act."

b. The death of an individual shall be declared in accordance with the provisions of this act.

2. An individual who has sustained irreversible cessation of all circulatory and respiratory functions, as determined in accordance with currently accepted medical standards, shall be declared dead.

3. Subject to the standards, procedures and exemptions established in accordance with sections 4, 5, and 6 of this act, an individual whose circulatory and respiratory functions can be maintained solely by artificial means, and who has sustained irreversible cessation of all functions of the entire brain, including the brain stem, shall be declared dead.

4. a. A declaration of death upon the basis of neurological criteria pursuant to section 3 of this act shall be made by a licensed physician professionally qualified by specialty or expertise, in accordance with currently accepted medical standards and additional requirements, including appropriate confirmatory tests, as are provided pursuant to this act.

b. Subject to the provisions of this act, the Department of Health, jointly with the Board of Medical Examiners, shall adopt, and from time to time revise, regulations or interpretive guidelines setting forth (1) requirements, by specialty or expertise, for physicians authorized to declare death upon the basis of neurological criteria; and (2) currently accepted medical standards, including criteria, tests and procedures, to govern declarations of death upon the basis of neurological criteria. The initial regulations and interpretive guidelines shall be issued within 120 days of the enactment of this act.

c. If the individual to be declared dead upon the basis of neurological criteria is or may be an organ donor, the physician who makes the declaration that death has occurred shall not be the organ transplant surgeon, the attending physician of the organ recipient, nor otherwise an individual subject to a potentially significant conflict of interest relating to procedures for organ procurement.

d. If death is to be declared upon the basis of neurological criteria, the time of death shall be upon the conclusion of definitive clinical examinations and any confirmation necessary to determine the irreversible cessation of all functions of the entire brain, including the brain stem.

5. The death of an individual shall not be declared upon the basis of neurological criteria pursuant to sections 3 and 4 of this act when such a declaration would violate the personal religious beliefs or moral convictions of that individual and when that fact has been communicated to, or should, pursuant to the provisions of section 6, reasonably be known by, the licensed physician authorized to declare death. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of traditional cardio-respiratory criteria pursuant to section 2 of this act.

6. a. Prior to declaring an individual dead upon the basis of neurological criteria pursuant to sections 3 and 4 of this act, the licensed physician authorized to declare death, or another responsible person designated for that purpose, shall make reasonable efforts, in good faith, to determine whether this declaration would violate the personal religious beliefs or moral convictions of that individual. These efforts shall include, as is appropriate under the circumstances, review of available medical records, including advance directives for health care, and reasonable efforts to contact a person or persons, such as a family member, personal physician, religious leader, or friend, who maintained a close association with the individual sufficient to render that person knowledgeable concerning the nature and content of the individual's personal religious beliefs or moral convictions.

b. If a claim of exemption is reasonably advanced on the individual's behalf under this act, a physician or other health care provider responsible for the treatment and care of that individual shall:

(1) refrain from declaring the individual dead upon the basis of neurological criteria; and

(2) refrain from discontinuing, solely upon the basis of the individual's neurological status, mechanical or other artificial means employed to maintain the individual's circulatory or respiratory functions.

7. A licensed health care practitioner, hospital, or the health care provider who acts in good faith and in accordance with currently accepted medical standards to execute the provisions of this act and any rules, regulations or guidelines issued by the Department of Health or the Board of Medical Examiners pursuant to this act, shall not be subject to criminal or civil

liability or to discipline for unprofessional conduct with respect to those actions. These immunities shall extend to conduct in conformity with the provisions of this act following enactment of this act but prior to its effective date.

8. Changes in pre-existing criteria for the declaration of death effectuated by the legal recognition of modern neurological criteria shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual solely because of that individual's personal religious beliefs or moral convictions regarding the application of neurological criteria for declaring death.

9. a. Pursuant to the "Administrative Procedure Act", P.L.1968, c.410 (C.52:14B-1 et seq.) the Department of Health shall establish rules, regulations, policies and practices as may be necessary to collect annual reports from health care institutions, to gather additional data as is reasonably necessary, to oversee and evaluate the implementation of this act, including provisions relating to the exemption procedure established pursuant to sections 5 and 6 of this act. The department shall seek to minimize the burdens of record-keeping imposed by these rules, regulations, policies and practices, and shall seek to assure the appropriate confidentiality of patient records.

b. The Department of Health, the Board of Medical Examiners, and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care shall jointly evaluate the implementation of this act and report to the Legislature, including recommendations for any changes deemed necessary, within five years from the effective date of this act.

10. If any provision of this act or its application to any individual or circumstance is held invalid, the invalidity shall not affect other provisions or applications of this act which can be given effect without the invalid provision or application, and to this end the provisions of this act are severable.

11. This act shall take effect on the 180th day following the date of its enactment.

STATEMENT

This bill, "The New Jersey Declaration of Death Act", sets forth the provisions for declaring an individual dead. An individual who has sustained irreversible cessation of all circulatory and respiratory functions shall be declared dead. An individual whose circulatory and respiratory functions can only be maintained by artificial means, and who has sustained irreversible cessation of all functions of the entire brain shall only be declared dead upon the basis of neurological criteria by a qualified licensed physician.

The Department of Health with the Board of Medical Examiners shall adopt regulations or guidelines setting forth the professional requirements of physicians authorized to make a declaration of death upon the basis of neurological criteria and set forth the medical standards, tests and procedures by which to declare someone dead.

Where an individual is a potential organ donor, the physician making the determination of death may not be the surgeon for the organ transplant or the attending physician of the organ recipient or otherwise be in a conflict of interest.

The bill sets forth an exemption to accommodate the personal religious beliefs or moral convictions of the individual. An individual shall not be declared dead based on neurological criteria if the determination would violate his beliefs or convictions and that fact has been communicated to the physician or should be known by the physician authorized to make the determination of death. The physician shall make reasonable efforts to determine if the individual's beliefs or convictions would be violated by reviewing the medical records and contacting another person who maintained a close association with the individual so as to know the individual's religious beliefs or moral convictions.

The bill sets forth immunity from criminal or civil liability for any health care provider who acts in good faith in accordance with this bill.

The bill is not intended to impair or modify any health or life insurance policy or governmental benefits program. Nor shall coverage be denied solely on the basis of an individual's beliefs regarding the neurological criteria for determining death.

The Department of Health, State Board of Medical Examiners and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care shall monitor and evaluate the bill and report to the Legislature within five years.

HEALTH

Enacts the "New Jersey Declaration of Death Act."

ASSEMBLY, No. 2466

STATE OF NEW JERSEY

Introduced Pending Technical Review by Legislative Counsel

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Assemblywoman RANDALL

AN ACT concerning the care and treatment of persons who are terminally ill.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. This act shall be known and may be cited as the "Medical Power of Attorney and Treatment Decision Act."

2. This act is to be administered strictly in accordance with the general principles set forth in this section, which are declared to be the public policy of this State:

a. The State has an important interest in preserving and protecting life. Any doubts which arise under any of the treatment decision procedures as set forth in this act shall be resolved on the side of preserving life.

b. A person's interest in the integrity of his body is protected by the doctrine of informed consent which acknowledges a competent adult's right to decline to have any medical treatment initiated or continued.

c. This right of self-determination may give way if the person's treatment decision would adversely and directly affect the health, safety, or security of others.

d. It is the policy of this State that handicapped persons be accorded the same dignity, respect and legal rights which are accorded all other persons. Accordingly, decisions to withhold or withdraw life-sustaining treatment shall not be based upon assessment of the personal worth or social utility of a patient's life to others.

e. This right of self-determination presupposes a person's competency to make a rational and considered choice after examining the nature of the treatment, the risks, and alternative therapies.

f. In order to insure that this right of self-determination continues to be meaningful if a person becomes unable to actively participate in a decision to have medical treatment initiated or continued, the law of this State recognizes the right of a competent adult person to make a written directive instructing his physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition, as well as the right to make a written directive reaffirming that life-sustaining procedures should be continued or initiated. The law of this State also recognizes a written medical power of attorney directive. The medical procedure or intervention necessary to stabilize a patient in an emergency situation. The provision of food and fluids shall be continued unless the attending physician has made a specific determination that the continuation would be medically inappropriate.

i. "Nursing Home" means a health care facility which is under the jurisdiction of the Nursing Home Administrator's Licensing Board established by P.L.1968, c.356 (C.30:11-11) et seq. as that board was transferred to and vested in the State Department of Health pursuant to section 2 of P.L.1972, c.109 (C.26:2H-28).

j. "Patient" means a person of any age who is under the care of a physician and is receiving treatment or care in any health care facility.

k. "Physician" means a physician or surgeon licensed to practice medicine and surgery by the State Board of Medical Examiners.

l. "Terminal condition" means an incurable or irreversible condition or combination of conditions that will result within a relatively short time in death.

m. "Witness" means a person of at least 18 years of age not related to the person by blood or marriage and who would not be entitled to any portion of the estate of the person upon his decease under any will of the person or by operation of law. In addition, a witness to a directive shall not be the attending physician, an employee of the attending physician or a health facility in which the person is a patient or any person who is financially responsible for the person's medical care.

4. a. Any competent adult may execute a directive stating that his wish would be that life-sustaining procedures either be (1) withheld or withdrawn, or (2) continued or initiated in the event that he becomes unable to participate in treatment decisions when he is terminally ill. The directive must be signed by the person in the presence of two subscribing witnesses who shall attest that the declarant appears to be of sound mind and under no constraint or undue influence.

b. A physican who is provided a copy of a directive shall make it part of the person's medical record.

c. A directive may, but need not, be in the following forms, except that there shall be two witnesses who shall attest to the declarant's being of sound mind:

REFUSAL OF LIFE-SUSTAINING PROCEDURES
DIRECTIVE TO PHYSICIANS

I declare that if I should have an incurable or irreversible condition or combination of conditions that will cause my death within a relatively short time, it is my desire that my life not be prolonged by administration of life-sustaining procedures. If this occurs and I am unable to participate in decisions

Revocation does not preclude the person from issuing a subsequent directive either pursuant to this section or pursuant to section 5 of this act.

5. a. Any competent adult may execute a medical power of attorney directive authorizing his agent to make decisions that would effectuate what the agent believes would be his wish that life-sustaining procedures either be (1) withheld or withdrawn or (2) continued or initiated in the event that he becomes unable to participate in treatment decisions when he is terminally ill. In the event a person executes both a directive pursuant to section 4 of this act and a medical power of attorney directive pursuant to this section, the agent's role shall be limited to effectuating the wishes as stated in the directive executed pursuant to section 4. The medical power of attorney directive must be signed by the person in the presence of two subscribing witnesses who shall attest that the declarant is of sound mind and under no constraint or undue influence.

b. A physician who is provided a copy of the medical power of attorney directive shall make it a part of the person's medical record.

c. A medical power of attorney directive may, but need not, be in the following form, except that there shall be two witnesses who shall attest to the declarant's being of sound mind:

MEDICAL POWER OF ATTORNEY DIRECTIVE

I declare that if I should have an incurable or irreversible condition or combination of conditions that will cause my death within a relatively short time and I am unable to participate in decisions regarding my medical treatment,

I appoint ....
(Name) .... residing
at ....
(Street and Number, City and State)
....
(and telephone number, if available) ....
to decide whether to withhold, withdraw, continue, or begin life-sustaining procedures on my behalf.

I trust this person's judgment, have discussed this matter with the person, and believe this person, as my agent, will be able to choose a course of treatment for me that I would have chosen for myself.

Signed this...........day of........................, ...
Signature ....
City, County and State of Residence ....
....

We certify that declarant voluntarily signed this document in our presence and, to the best of our knowledge, the declarant is of sound mind and under no

f. No physician, health facility, or other health provider, and no health care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan, or nonprofit hospital plan, shall require any person to execute a directive as a condition for being insured for, or receiving, health care services.

g. Health care facilities shall make forms, as set forth in sections 4 and 5 of this act, available to all patients admitted to the facility. Sample forms may be provided to patients at the time of admission or other notice shall be provided in the health care facilities' discretion in a means reasonably calculated to inform admitted patients of the availability of the forms.

7. a. A person believing that life-sustaining treatment should be withheld or withdrawn from a patient in a terminal condition who is no longer able to make his own treatment decision may bring the matter to the attention of the patient's attending physician if he believes:

(1) The patient has either executed a directive pursuant to section 4 of this act to that effect, or

(2) The patient has named him in a directive executed pursuant to section 5 of this act and has indicated that course of action would be his choice.

If the attending physician finds that the patient's medical prognosis is terminal and has sufficient indication that a directive exists indicating the patient's choice would be to withhold or withdraw life-sustaining procedures, the attending physician shall obtain the independent evaluation of two other physicians who have personally examined the patient.

b. Persons who may bring the application for withholding or withdrawal of procedures in the first instance to the attending physician are:

(1) The person named in a medical power of attorney directive executed pursuant to section 5 of this act; if there is no agent or the agent is unable or unwilling to act, then;

(2) A family member, legal guardian or friend of the patient; if there is no family, legal guardian or friend then:

(3) An employee of the health care facility where the patient is admitted who has been involved in the patient's care; or

(4) In the absence of all of the above, the attending physician may directly take the matter to two other physicians for evaluation in accordance with the issues set forth is section 9 of this act.

8. a. For patients for whom the Ombudsman for the Institutional Elderly may act under P.L.1977, c.239 (C.52:27G-1 et seq.), and notwithstanding any provisions of P.L.1977, c.239 (C.52:27G-1 et seq.) to the contrary, for patients of any age residing in a nursing home the Ombudsman shall conduct an investigation in accordance with this section; and

b. (1) For mentally ill persons in institutions for which the Public Advocate may act pursuant to P.L.1974, c.27 (C.52:27E-1

c. Has that patient executed a directive which either indicates treatment should be withdrawn or withheld or which names an agent who is authorizing the withdrawal or withholding; and

d. Does that patient have an incurable or irreversible condition or combination of conditions in the independent medical judgment of the two physicians; and

e. If the condition is incurable or irreversible, will it result in death in a relatively short time.

If the attending physician and two other physicians find that the five issues stated above are answered affirmatively, then the physicians shall concur in the treatment decisions expressed in the directive executed pursuant to section 4 of this act or in the treatment decision of the agent appointed by the directive executed pursuant to section 5 of this act.

10. a. If any one of the three physicians acting pursuant to section 9 of this act finds any of the issues set forth in that section to be answered in the negative, then life-sustaining procedures shall be continued. That decision shall be deemed final for the purposes of appeal to the Superior Court. The standard of review shall be whether the physicians acted arbitrarily and capriciously as demonstrated by clear and convincing evidence. Any appeal taken shall be filed within 14 business days of this final decision. The appropriate health care facility shall be served notice of the appeal simultaneously with the filing of the complaint.

b. Nothing this section shall be deemed to preclude further evaluation of a patient pursuant to section 9 of this act where there is a sufficient change of circumstances to warrant reconsideration.

11. In the absence of actual notice of the revocation of the directive to physicians or medical power of attorney directive, none of the following, when acting in accordance with the requirements of this act, shall be subject to civil liability therefrom, or shall be guilty of any criminal act or of unprofessional conduct:

a. A physician or health care facility which participates in the decision to withhold or withdraw life-sustaining procedures from a patient.

b. A physician and a licensed health professional acting under the direction of a physician, or both, who participate in the withholding or withdrawal of life-sustainingprocedures.

12. The withholding or withdrawal of life-sustaining procedures from a patient in accordance with the provisions of this act shall not, for any purposes, constitute a suicide and shall not constitute the crime of aiding suicide as prohibited by N.J.S.2C:11-6.

13. Directives executed in accordance with the requirements set forth in this act are entitled to a presumption of validity.

14. Notwithstanding the specific requirements set forth in this

CIVIL JUSTICE

The "Medical Power of Attorney and Treatment Decision Act," establishes a procedure through which an individual can control decisions regarding continuation of artificial life-support systems when suffering from a terminal condition.

ASSEMBLY, No. 2467

STATE OF NEW JERSEY

Introduced Pending Technical Review by Legislative Counsel

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Assemblywoman RANDALL

AN ACT concerning surrogate decision making for certain persons who are terminally ill or in certain persistent states, amending P.L.1977, c.239 and supplementing Title 26 of the Revised Statutes.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. (New section) As used in this act:

a. "Attending physician" means the physician, selected by or assigned to the patient, who has primary responsibility for the treatment and care of the patient and who is familiar with the patient.

b. "Directive" means a written document voluntarily executed by a person in accordance with the requirements of P.L. , c. , (C.) (now pending before the Legislature as Assembly Bill No. of 1988). The directive, or a copy of the directive, may be made part of the person's medical records. The term includes both the directive to physicians and the medical power of attorney directive.

c. "Independent physician" means a physician who does not have primary responsibility for the treatment and care of the patient but who consults on the patient's case after examining the patient and the patient's medical history.

d. "Life-sustaining treatment" means any medical procedure which utilizes mechanical or other artificial means to sustain, restore or supplant a vital human bodily function.

e. "Persistent vegetative state" means a condition where the body can maintain only the vegetative parts of neurological functions and where there is no reasonable hope that cognitive capacity will be regained.

f. "Terminally ill" means having an incurable condition caused by injury, disease or illness which, within reasonable medical judgment, will ultimately produce death and the application of life-sustaining treatment serve only to postpone the moment of death.

2. (New section) a. A person believing that life-sustaining treatment should be withheld or withdrawn from a patient who is unable to make his own treatment decision when he is terminally ill or in a persistent vegetative state and where the patient has

EXPLANATION—Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted in the law.

Matter underlined thus is new matter.

not executed any directive, may bring the matter to the attention of the patient's attending physician and seek to act as surrogate decision maker for the patient.

b. Persons who may bring the application for withholding or withdrawal of treatment where there is no executed directive are:

(1) the patient's spouse; or

(2) if there is no spouse, one of the patient's adult children; or

(3) if there are no adult children, then either one of the patient's parents; or

(4) if there is no parent, then one of the patient's siblings; or

(5) if there is no sibling, then the next most closely-related family member who functions in the role of the patient's nuclear family.

3. (New section) a. The factors to be considered by the surrogate decision maker shall include, but are not limited to, the following:

(1) the patient's personal value system;

(2) facets of the patient's personality;

(3) the patient's religious beliefs and tenets of that religion;

(4) whether the tenets of the patient's religion are generally in accordance with the definition of death as stated in P.L. , c. (C.) (now pending before the Legislature as Senate Bill No. of 1988 or Assembly Bill No. of 1988);

(5) the patient's consistent pattern of conduct with respect to medical care;

(6) the patient's comments as to his beliefs regarding medical treatment or his reactions to treatment administered to others;

(7) comments by any of the persons listed in subsection b. of section 2 of this act concerning any of the factors set forth in this subsection; and

(8) comments by any other person who was acquainted with the patient on a personal or professional basis concerning the patient's comments about his own medical care.

b. The test to be applied by the family surrogate decision maker following due consideration of all factors set forth in subsection a. of this section is what would the patient have done if able to choose for himself, not what a reasonable or average person would have chosen to do under the circumstances.

4. (New section) If there are no persons to act on behalf of the patient as listed in subsection b. of section 2 of this act and the patient has not executed a directive, then an application for the appointment of a medical guardian may be made to the Superior Court by the attending physician or another interested party. If appropriate, the court may appoint the Public Guardian as

guardian pursuant to section 7 of P.L.1985, c.298 (C.52:27G-26). The medical guardian may act as surrogate decision maker. This surrogate decision maker shall consider as many of the factors set forth in subsection a. of section 3 of this act as are practicable. Nothing in this act shall preclude the surrogate decision maker from seeking guidance from an appropriate hospital ethics or prognosis committee.

5. (New section) When there is any application to withhold or withdraw life-sustaining treatment by any surrogate decision maker and there is no need to comply with the investigation procedures set forth in section 6 of this act, then the decision maker shall obtain statements from two independent physicians knowledgeable in neurology that:

a. the patient is in a persistent vegetative state; and

b. there is no reasonable possibility that the patient will ever recover to a cognitive, sapient state.

The attending physician shall also submit a statement to this effect.

6. (New section) a. For patients for whom the Ombudsman for the Institutionalized Elderly may act under P.L.1977, c.239 (C.52:27G-1 et seq.), the Ombudsman shall conduct an investigation in accordance with this section.

(1) for mentally ill persons in institutions for the Public Advocate may act pursuant to P.L.1974, c.27 (C.52:27E-1 et seq.); and

(2) for disabled persons who reside in an institution for the developmentally disabled or mentally ill or any other facility specializing in serving persons with disabilities, licensed or operated by the Department of Human Services for whom the Public Advocate may act pursuant to P.L. 1981, c. 444 (C. 52:27E-41.1 et seq.), the Public Advocate shall conduct an investigation in accordance with this section.

b. When an application for the withdrawing or withholding of life-sustaining treatment has been made by a surrogate decision maker on behalf of any person residing in a health care facility other than a hospital, the chief administrator of the facility shall give notice to the Ombudsman for the Institutionalized Elderly, or the Public Advocate in accordance with the jurisdiction set forth in subsections a. and b. of this section. It shall be the responsibility of the Public Advocate or the Ombudsman for the Institutionalized Elderly, as the case may be, to refer notice inappropriately filed with either agency to the other agency.

c. The Ombudsman for the Institutionalized Elderly or the Public Advocate shall obtain statements from two independent physicians who have evaluated the patient's medical condition. These statements shall include: the medical alternatives available, the risks involved, the likely outcome if medical treatment is discontinued and the lack of reasonable possibility that the patient will recover to a cognitive, sapient state.

d. The Ombudsman or the Public Advocate shall defer to a determination made by a surrogate decision maker, if there is clear and convincing evidence that the patient's wishes are sufficiently known to the surrogate decision maker who:

(1) has been appointed by directive; or

(2) who is one of the persons listed in subsection b. of section 2 of this act; or

(3) has been appointed as medical guardian pursuant to section 4 of this act.

e. If there is no clear and convincing evidence to persuade the Ombudsman or the Public Advocate in accordance with subsection e. of this section then a surrogate decision maker's application to withhold or withdraw life-sustaining treatment shall be approved if one of the following tests is satisfied:

(1) it is clear that the patient would have refused the treatment under the circumstances;

(2) there is some trustworthy evidence that the patient would have refused the treatment, and that the pain and suffering with the treatment markedly outweigh the benefits of any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from that life; or

(3) the pain and suffering of the patient's life with the treatment clearly and markedly outweigh the benefits that the patient derives from life, and the patient is suffering from so much pain that it would be inhumane to prolong life.

f. Life-sustaining treatment shall not be withdrawn or withheld until notice has been received from the Ombudsman or the Public Advocate informing the administrator of the health care facility that the investigation is complete and that there is no opposition to the withdrawing or withholding of life-sustaining treatment.

7. Section 2 of P.L.1977, c.239 (C.52:27G-2) is amended to read as follows:

2. As used in this act, unless the context clearly indicates otherwise:

a. "Abuse" means the willful infliction of physical pain, injury or mental anguish; unreasonable confinement; or the willful deprivation of services which are necessary to maintain a person's physical and mental health. However, no person shall be deemed to be abused for the sole reason he is being furnished nonmedical remedial treatment by spiritual means through prayer alone, in accordance with a recognized religious method of healing, in lieu of medical treatment;

b. An "act" of any facility or government agency shall be deemed to include any failure or refusal to act by such facility or government agency;

c. "Administrator" means any person who is charged with the general administration or supervision of a facility, whether or not such person has an ownership interest in such facility, and whether or not such person's functions and duties are shared with one or more other persons;

d. "Caretaker" means a person employed by a facility to provide care or services to an elderly person, and includes, but is not limited to, the administrator of a facility;

e. "Exploitation" means the act or process of using a person or his resources for another person's profit or advantage without legal entitlement to do so;

f. "Facility" means any facility or institution, whether public or private, offering health or health related services for the institutionalized elderly, and which is subject to regulation, visitation, inspection, or supervision by any government agency. Facilities include, but are not limited to, nursing homes, skilled nursing homes, intermediate care facilities, extended care facilities, convalescent homes, rehabilitation centers, residential health care facilities, special hospitals, veterans' hospitals, chronic disease hospitals, psychiatric hospitals, mental hospitals, mental retardation centers or facilities, day care facilities for the elderly and medical day care centers;

g. "Government agency" means any department, division, office, bureau, board, commission, authority, or any other agency or instrumentality created by the State or to which the State is a party, or by any county or municipality, which is responsible for the regulation, visitation, inspection or supervision of facilities, or which provides services to patients, residents or clients of facilities;

h. "Guardian" means any person with the legal right to manage the financial affairs and protect the rights of any patient, resident or client of a facility, who has been declared a mental incompetent by a court of competent jurisdiction;

i. "Institutionalized elderly," "elderly" or "elderly person" means any person 60 years of age or older, who is a patient, resident or client of any facility except that, with respect to a person who has a surrogate decision maker acting for them in accordance with the provisions of P.L. , c. . (C.) (now pending before the Legislature as this bill) the person may be one of any age who is a patient, resident or client of any facility;

j. "Office" means the Office of the Ombudsman for the Institutionalized Elderly established herein;

k. "Ombudsman" means the administrator and chief executive officer of the Office of the Ombudsman for the Institutionalized Elderly;

l. "Patient, resident or client" means any elderly person who is receiving treatment or care in any facility in all its aspects, including, but not limited to, admission, retention, confinement, commitment, period of residence, transfer, discharge and any instances directly related to such status.

8. (New section) The withholding or withdrawal of life-sustaining treatment from a patient in accordance with the provisions of this act shall not, for any purpose, constitute a suicide and shall not constitute the crime of aiding suicide as prohibited by N.J.S.2C:11-6.

9. (New section) a. A health care facility and its employees shall be immune from civil or criminal liability when acting in good faith and in accordance with generally accepted medical practices and in accordance with the provisions of this act.

b. A surrogate decision maker shall be immune from civil or criminal liability when acting in good faith and in accordance with the provisions of this act.

10. (New section) Nothing in this act shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining treatment in any lawful manner. In this respect the provisions of this act are cumulative.

11. This act shall take effect on the 60th day after enactment.

STATEMENT

This bill establishes a procedure through which a person suffering from a terminal condition, or in a persistent vegetative state, who has become unable to make a treatment decision for himself, can exercise his personal right to control the use of life-sustaining treatment. The bill's use of the term "directive" refers to the directive recognized by a companion bill which will be introduced in 1988.

When a person has not executed a directive to physicians or a medical power of attorney, a surrogate decision maker who believes that the incompetent patient would have wanted treatment withdrawn or withheld may bring the matter to the attention of the attending physician. The bill establishes a hierarchy of who may act as a surrogate decision maker.

The bill sets forth as the test to be used in determining treatment decision, what the patient would have chosen for himself.

The decision maker shall obtain statements from two independent physicians that the patient is in a persistent vegetative state and that there is no reasonable possibility that the patient will ever recover to a cognitive, sapient state. The attending physician shall also submit a statement to this effect.

The bill recognizes the role of the Ombudsman for the Institutionalized Elderly and the Public Advocate with respect to certain persons confined to institutions.

CIVIL JUSTICE

Provides for the withholding of life-sustaining treatment in the absence of a medical directive or power of attorney.

ASSEMBLY, No. 2492

STATE OF NEW JERSEY

Introduced Pending Technical Review by Legislative Counsel

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Assemblywoman RANDALL and Assemblyman SCHUBER

AN ACT concerning health treatment decisions and supplementing Title 26 of the Revised Statutes.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. This act shall be known and may be cited as the "New Jersey Health Care Directive Act."

2. The legislature finds and declares that individuals have the fundamental right to determine whether to receive health care, and that the right to have specific treatment or procedures initiated, withheld or withdrawn, including life-sustaining procedures, is in accord with the public policy of this State.

3. As used in this act:

a. "Declarant" means the person who executes a Treatment Directive or Medical Decision Power of Attorney.

b. "Health care" means medical, surgical, hospital, psychiatric, nursing, nursing home, hospice, custodial and other similar care provided to a declarant which affects his or her physical or mental condition and well-being.

c. "Health care provider" means any person or entity providing health care to a declarant.

d. "Life-sustaining procedure" means any health care which is or may be essential for the prolongation of the declarant's life.

e. "Medical Decision Power of Attorney" means a written document executed in accordance with the requirements of section 5 of this act, which appoints another individual or individuals as attorneys-in-fact to make health care decisions for the declarant.

f. "Treatment Directive" means a written document, executed in accordance with the requirements of section 4 of this act, which provides guidelines or directives with respect to a declarant's health care, including but not limited to, provisions for initiating, continuing, withholding or withdrawing any or all life sustaining procedures.

4. Any competent adult may execute a Treatment Directive. The directive shall either:

a. Be signed by the declarant, or another at the declarant's direction, in the presence of two witnesses, who shall sign as such in the presence of the declarant; or

b. Be signed by the declarant, or another at the declarant's direction, and be acknowledged before a notary public, attorney-at-law or other person authorized to administer oaths.

pregnancy has reached the third trimester.

b. Where the pregnancy has reached the third trimester or where the Treatment Directive or Medical Decision Power of Attorney does not contain a specific provision relating to the contingency of pregnancy as provided for in subsection a. of this section, a consultation by an appropriate medical specialist shall be obtained to determine whether, to a reasonable medical certainty, the fetus could develop to the point of live birth with continued application of life-sustaining treatment. If the medical consultation concludes that the fetus would so develop, then the Treatment Directive or Medical Decision Power of Attorney shall not be effective to withhold or withdraw life-sustaining treatment and the decision whether to withhold or withdraw life-sustaining treatment shall not be controlled by the provisions of this act. The Treatment Directive or Medical Decision Power of Attorney shall become effective upon birth or a finding to a reasonable medical certainty that the fetus has expired or is unable to develop to the point of live birth with the continued application of life-sustaining treatment.

9. A Treatment Directive or Medical Decision Power of Attorney may be revoked at any time by the declarant, or by another at the declarant's direction, by written instrument executed with the formalities provided by sections 4 or 5 of this act, or by destruction of the document by the declarant or at the declarant's direction.

10. A health care provider who is unwilling to comply with a Treatment Directive or the directions of an attorney-in-fact pursuant to a Medical Decision Power of Attorney shall, as promptly as practicable, take all reasonable steps to transfer care of the declarant to another health care provider who is willing to comply.

11. a. Unless otherwise provided by law, in the absence of knowledge of revocation, a person or health care provider is not subject to civil or criminal liability or discipline for unprofessional conduct for complying with a Treatment Directive, or complying with the instructions of the attorney-in-fact acting pursuant to a Medical Decision Power of Attorney.

b. A physician or other health care provider whose actions under this act are in accord with reasonable medical standards is not subject to criminal or civil liability or discipline for unprofessional conduct.

12. A person is guilty of a crime of the fourth degree if he:

a. Willfully conceals, cancels, defaces, or obliterates a Treatment Directive or Medical Decision Power of Attorney, or a revocation thereof, without the declarant's consent.

b. Falsifies or forges a Treatment Directive or Medical Decision Power of Attorney, or a revocation thereof, or conceals or withholds personal knowledge of a revocation.

the requirements of this act.

17. If any provision of this act or its application to any person or circumstance is held invalid, the invalidity shall not affect other provisions or applications of this act which can be given effect without the invalid provision or application, and to that end the provisions of this act are severable.

18. This act shall take effect immediately.

STATEMENT

This bill is intended to provide two mechanisms by which an individual can exercise the fundamental right to determine whether or not to receive health care, and the right to have specific treatment or procedures initiated, withheld or withdrawn, in the event the individual becomes unable to make his own health care decisions. This bill is not intended to create new rights or expand or limit existing or future substantive legal limitations on a declarant's right to receive or refuse to receive health care.

The first, a Treatment Directive, has commonly come to be known as a "living will." The second, a Medical Decision Power of Attorney, is a power of attorney authorizing another to make health care treatment decisions.

Some indivuals may wish to specify their treatment decisions in a Treatment Directive and have those desicions followed in the event they become unable to act. However, it is often impossible for an individual, in advance of an illness or in advance of commencing a course of health care treatment, to anticipate all of the circumstances which may influence treatment care decision, and it may be difficult to execute a Treatment Directive covering all treatment decisions. Instead, many individuals may wish to entrust some or all treatment decisions to a trusted person acting under a Medical Decision Power of Attorney.

Under the provisions of the bill any competent individual may execute a Treatment Directive or a Medical Decision Power of Attorney, or both. If the declarant wishes to have life-sustaining treatment withheld or withdrawn, the document must specifically state so. A Treatment Directive or a Medical Decision Power of Attorney may be revoked at any time. In the event a health care provider is unwilling to comply with a Treatment Directive or Medical Decision Power of Attorney, the provider shall take all reasonable steps to transfer the declarant to another health care provider. The bill also makes provision for a pregnant declarant and provides immunity from all civil or criminal liability for complying with the Treatment Directive or Medical Power of Attorney.

ASSEMBLY, No. 2514

STATE OF NEW JERSEY

Introduced Pending Technical Review by Legislative Counsel

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Assemblywoman RANDALL and Assemblyman NAPLES

AN ACT concerning health care decision making.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. This act shall be known and may be cited as the "New Jersey Advance Directives for Health Care Act."

2. The Legislature finds and declares that:

a. Competent adults have the fundamental right, in collaboration with their health care providers, to control decisions about their own health care. This State recognizes, in its law and public policy, the personal right of the individual patient to make voluntary, informed choices to accept, to reject, or to choose among alternative courses of medical and surgical treatment.

b. Modern advances in science and medicine have made possible the prolongation of the lives of many seriously ill individuals, without always offering realistic prospects for improvement or cure. For some individuals the possibility of extended life is experienced as meaningful and of benefit. For others, artificial prolongation of life may seem to provide nothing medically necessary or beneficial, serving only to extend suffering and prolong the dying process. This State recognizes that the fundamental right of individual choice extends to decisions to have life-prolonging medical or surgical means or procedures provided, withheld, or withdrawn.

c. In order that the right to control decisions about one's own health care should not be lost in the event a patient loses decision making capacity and is no longer able to participate actively in making his own health care decisions, this State recognizes the right of competent adults to plan ahead for health care decisions through the execution of advance directives, such as living wills and durable powers of attorney, and to have the wishes expressed therein respected, subject to certain limitations.

d. The right of individuals to forego life-sustaining measures is subject to certain interests of society. The most significant of these societal interests is the preservation of life, understood to embrace both an interest in preserving the life of the particular patient and a related but distinct interest in preserving the sanctity of all human life as an enduring social value. A second, closely related societal interest is the protection of individuals from direct and purposeful self-destruction, motivated by a specific intent to die. A third interest is the protection of innocent third parties who may be harmed by the patient's decision to forego therapy; this interest may be asserted to prevent the emotional and financial abandonment of the patient's minor children or to protect the paramount concerns of public health or safety. A fourth interest encompasses safeguarding the ethical integrity of the health care professions, individual professionals, and health care institutions, and maintaining public confidence and trust in the integrity and caring role of health care professionals and institutions. Finally, society has an interest in ensuring the soundness of health care decision making, including both protecting vulnerable patients from potential abuse or neglect and facilitating the exercise of informed and voluntary patient choice.

e. In accordance with these State interests, this State expressly rejects on both legal and moral grounds the practice of active euthanasia, as by deliberate lethal injection intended to cause death. No individual shall have the right to, nor shall any physician or other health care professional be authorized to engage in, the practice of active euthanasia.

f. In order to assure respect for patients' previously expressed wishes when the capacity to participate actively in decision making has been lost or impaired; to facilitate and encourage a sound decision making process in which patients, health care representatives, families, physicians, and other health care professionals are active participants; to properly consider patients' interests both in self-determination and in well-being; and to provide necessary and appropriate safeguards concerning the termination of life-sustaining treatment for incompetent patients as the law and public policy of this State, the Legislature hereby enacts the New Jersey Advance Directives for Health Care Act.

3. As used in this act:

"Adult" means an individual 18 years of age or older.

"Advance directive for health care" or "advance directive" means a writing executed in accordance with the requirements of this act. An "advance directive" may include a proxy directive or an instruction directive, or both.

"Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

"Decision making capacity" means a patient's ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of each, and alternatives to any proposed health care, and to reach an informed decision. A patient's decision making capacity is evaluated relative to the demands of a particular health care decision.

"Declarant" means a competent adult who executes an advance directive.

"Do not resuscitate order" means a physician's written order not to attempt cardiopulmonary resuscitation in the event the patient suffers a cardiac or respiratory arrest.

"Emergency care" means immediate treatment provided in response to a sudden, acute and unanticipated medical crisis in order to avoid injury, impairment or death.

"Health care decision" means a decision to accept or to refuse any treatment, service or procedure used to diagnose, treat or care for a patient's physical or mental condition, including life-sustaining treatment. "Health care decision" also means a decision to accept or to refuse the services of a particular physician, nurse, other health care professional or health care institution, including a decision to accept or to refuse a transfer of care.

"Health care institution" means all institutions, facilities, and agencies licensed, certified, or otherwise authorized by State law to administer health care in the ordinary course of business, including hospitals, nursing homes, residential health care facilities, home health care agencies, and hospice programs operating in this State, but does not include mental health institutions, facilities or agencies, or institutions, facilities or agencies for the developmentally disabled. The term "health care institution" shall not be construed to include "health care professionals" as defined in this act.

"Health care professional" means an individual licensed by this State to administer health care in the ordinary course of business or practice of a profession.

"Health care representative" means the individual designated by a declarant pursuant to the proxy directive part of an advance directive for the purpose of making health care decisions on the declarant's behalf, and includes an individual designated as an alternate health care representative who is acting as the declarant's health care representative in accordance with the terms and order of priority stated in an advance directive.

"Instruction directive" means a writing which may be a component of an advance directive and which provides instructions and direction regarding the declarant's wishes for health care in the event that the declarant lacks decision making capacity. An "instruction directive" may be referred to as a living will.

"Life-sustaining treatment" means the use of any medical device or procedure, drugs, surgery or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function, and thereby increase the expected life span of a patient.

"Other health care professionals" means health care professionals other than physicians and nurses.

"Patient" means an individual who is under the care of a physician, nurse or other health care professional.

"Permanently unconscious" means a medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term "permanently unconscious" includes without limitation a persistent vegetative state or irreversible coma.

"Physician" means an individual licensed to practice medicine and surgery in this State.

"Proxy directive" means a writing which may be a component of an advance directive and which designates a health care representative in the event the declarant lacks decision making capacity. A "proxy directive" may be referred to as a medical durable power of attorney.

"State" means a state, territory, or possession of the United States, the District of Columbia, or the Commonwealth of Puerto Rico.

"Terminal condition" means the terminal stage of an irreversibly fatal illness, disease or condition. A determination of a specific life expectancy is not required as a precondition for a diagnosis of a "terminal condition," but a prognosis of a life expectancy of six months or less, with or without the provision of life-sustaining treatment, based upon reasonable medical certainty, shall be deemed to constitute a terminal condition.

4. A declarant may execute an advance directive for health care at any time. The advance directive shall be signed and dated by, or at the direction of, the declarant in the presence of two subscribing adult witnesses, who shall attest that the declarant is of sound mind and free of duress and undue influence. A designated health care representative shall not act as a witness to the execution of an advance directive. An advance directive may be supplemented by a video or audio tape recording.

An advance directive may be made self-proved at the time of execution by following the formal requirements stated in N.J.S. 3B:3-4 for making a testamentary will self-proved.

5. a. A declarant may reaffirm or modify either a proxy directive, or an instruction directive, or both. The reaffirmation or modification shall be made in accordance with the requirements for execution of an advance directive pursuant to section 4 of this act.

b. A declarant, whether competent or incompetent, may revoke a prior proxy directive, or a prior instruction directive, or both, by the following means:

(1) Notification, orally or in writing, to the health care

representative, attending physician, nurse or other health care professional, or other reliable witness;

(2) Destruction or attempted destruction of the document, or other act evidencing an intent to revoke the document; or

(3) Execution of a subsequent proxy directive or instruction directive, or both, in accordance with section 4 of this act.

c. Designation of the declarant's spouse as health care representative shall be revoked upon divorce or legal separation, unless otherwise specified in the advance directive.

d. Reaffirmation, modification or revocation of an advance directive is effective upon communication to the health care representative, the attending physician, nurse or other health care professional responsible for the patient's care.

6. a. A declarant may execute a proxy directive, pursuant to the requirements of section 4 of this act, designating a competent adult to act as his health care representative.

(1) A competent adult, including, but not limited to, a declarant's spouse, adult child, parent or other family member, friend, religious or spiritual advisor, or other person of the declarant's choosing, may be designated as a health care representative.

(2) A declarant may not designate as a health care representative an operator, administrator or employee of a health care institution in which, at the time the advance directive is executed, the declarant is a patient or resident, or has applied for admission, unless the operator, administrator or employee is related to the declarant by blood, marriage or adoption.

This restriction does not apply to a physician, if the physician does not serve as the patient's attending physician and the patient's health care representative at the same time.

(3) A declarant may designate one or more alternate health care representatives, listed in order of priority. In the event the primary designee is unavailable, unable or unwilling to serve as health care representative, or is disqualified from such service pursuant to this section or any other law, the next designated alternate shall serve as health care representative. In the event the primary designee subsequently becomes available and able to serve as health care representative, the primary designee may, insofar as then practicable, serve as health care representative.

(4) A declarant may direct the health care representative to consult with specified individuals, including alternate designees, family members and friends, in the course of the decision making process.

(5) A declarant shall state the limitations, if any, to be placed upon the authority of the health care representative.

b. A declarant may execute an instruction directive, pursuant to the requirements of section 4 of this act, stating the declarant's general treatment philosophy and objectives; or the

declarant's specific wishes regarding the provision. withholding or withdrawal of any form of health care, including life-sustaining treatment; or both. An instruction directive may, but need not, be executed contemporaneously with, or be attached to, a proxy directive.

A declarant who chooses to instruct that artificially provided fluids and nutrition should be withheld or withdrawn under certain conditions shall so indicate by an explicit statement in the instruction directive.

7. a. An advance directive becomes operative when (1) it is transmitted to the attending physician or to the health care institution, and (2) it is determined pursuant to section 8 of this act that the patient lacks decision making capacity.

b. Treatment decisions pursuant to an advance directive shall not be made and implemented until there has been an reasonable opportunity to establish, and where appropriate confirm, a reliable diagnosis and prognosis for the patient.

8. a. The attending physician shall determine whether the patient lacks decision making capacity. The determination shall be stated in writing, shall include the attending physician's opinion concerning the nature, cause, extent, and probable duration of the patient's incapacity, and shall be made a part of the patient's medical records.

b. The attending physician's determination of a lack of decision making capacity shall be confirmed by one or more physicians. The opinion of the confirming physician shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician. Confirmation of a lack of decision making capacity is not required when the patient's lack of decision making capacity is clearly apparent, and the attending physician and the health care representative agree that confirmation is unnecessary.

c. If the attending physician or the confirming physician determines that a patient lacks decision making capacity because of a mental or psychological impairment or a developmental disability, and neither the attending physician or the confirming physician has specialized training or experience in diagnosing mental or psychological conditions or developmental disabilities of the same or similar nature, a determination of a lack of decision making capacity shall be confirmed by one or more physicians with appropriate specialized training or experience. The opinion of the confirming physician shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician.

d. A physician designated by the patient's advance directive as a health care representative shall not serve as the confirming physician for the determination of a lack of decision making capacity.

e. The attending physician shall inform the patient, if the patient has any ability to comprehend that he has been determined to lack decision making capacity, and the health care representative that: (1) the patient has been determined to lack decision making capacity to make a particular health care decision; (2) each has the right to contest this determination; and (3) each may have recourse to the dispute resolution process established by the health care institution pursuant to section 14 of this act.

Notice to the patient and the health care representative shall be documented in the patient's medical records.

f. A determination of lack of decision making capacity under this act is solely for the purpose of implementing an advance directive in accordance with the provisions of this act, and shall not be construed as a determination of a patient's incapacity or incompetence for any other purpose.

g. For purposes of this section, a determination that a patient lacks decision making capacity shall be based upon, but need not be limited to, evaluation of the patient's ability to understand and appreciate the nature and consequences of a particular health care decision, including the benefits and risks of, and alternatives to, the proposed health care, and to reach an informed decision.

9. a. A health care representative shall have legal authority to make health care decisions on behalf of the patient. The health care representative shall act in good faith and within the bounds of the authority granted by the advance directive and by this act.

b. If a different individual has been appointed as the patient's legal guardian, the health care representative shall retain legal authority to make health care decisions on the patient's behalf, unless the terms of the legal guardian's court appointment or other court decree provide otherwise.

c. The conferral of legal authority on the health care representative shall not be construed to impose liability upon the health care representative for any portion of the patient's health care costs.

d. An individual designated as a health care representative or as an alternate health care representative may decline to serve in that capacity.

e. The health care representative shall exercise the patient's right to be informed of the patient's medical condition, prognosis and treatment options, and to give informed consent to, or refusal of, health care.

10. In addition to any rights and responsibilities recognized or imposed by, or pursuant to, this act, or by any other law, physicians, nurses, and other health care professionals shall have the following rights and responsibilities:

a. The attending physician shall make an affirmative inquiry of the patient, his family or others, as appropriate under the circumstances, concerning the existence of an advance directive. The attending physician shall note in the patient's medical records whether or not an advance directive exists, and the name of the patient's health care representative, if any, and shall attach a copy of the advance directive to the patient's medical records. The attending physician shall document in the same manner the reaffirmation, modification, or revocation of an advance directive, if he has knowledge of such action.

b. A physician may decline to participate in the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life, in accordance with his sincerely held personal or professional convictions. In such circumstances, the physician shall act in good faith to inform the patient and the health care representative, and the chief of the medical staff or other designated institutional official, of this decision as soon as practicable, to effect an appropriate, respectful and timely transfer of care, and to assure that the patient is not abandoned or treated disrespectfully.

In the event of transfer of a patient's care, the attending physician shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

c. A nurse or other health care professional may decline to participate in the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life, in accordance with his sincerely held personal or professional convictions. In these circumstances, the nurse and other health care professional shall act in good faith to inform the patient and the health care representative, and the head of the nursing or other professional staff or other designated institutional official, of this decision as soon as practicable, to cooperate in effecting an appropriate, respectful and timely transfer of care, and to assure that the patient is not abandoned or treated disrespectfully.

d. Nothing in this act shall be construed to require a physician, nurse or other health care professional to begin, continue, withhold, or withdraw health care in a manner contrary to law or accepted professional standards.

11. a. The attending physician, the health care representative and, when appropriate, any additional physician responsible for the patient's care, shall discuss the nature and consequences of the patient's medical condition, and the risks, benefits and burdens of the proposed health care and its alternatives. Except as provided by subsection b. of this section, the attending physician shall obtain informed consent for, or refusal of, health care from the health care representative.

(1) Discussion of the proposed treatment and its alternatives

shall include, as appropriate under the circumstances, the availability, benefits and burdens of rehabilitative treatment, therapy, and services.

(2) The decision making process shall allow, as appropriate under the circumstances, adequate time for the health care representative to understand and deliberate about all relevant information before a treatment decision is implemented.

b. Following a determination that a patient lacks decision making capacity, the health care representative and the attending physician shall, to a reasonable extent, discuss the treatment options with the patient, and seek to involve the patient as a participant in the decision making process. The health care representative and the attending physician shall seek to promote the patient's capacity for effective participation and shall take the patient's expressed wishes into account in the decision making process.

If the patient is found to possess adequate decision making capacity with respect to a particular health care decision, the patient shall retain legal authority to make that decision. In such circumstances, the health care representative may continue to participate in the decision making process in an advisory capacity, unless the patient objects.

Notwithstanding any other provision of this act to the contrary, if a patient who lacks decision making capacity clearly expresses or manifests the contemporaneous wish that medically appropriate life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life be provided, that wish shall take precedence over any contrary decision of the health care representative and any contrary statement in the patient's instruction directive.

c. In acting to implement a patient's wishes pursuant to an advance directive, the health care representative shall give priority to the patient's instruction directive, and may also consider, as appropriate and necessary, the following forms of evidence of the patient's wishes:

(1) Reliable oral or written statements previously made by the patient, including, but not limited to, statements made to family members, friends, health care professionals or religious leaders;

(2) Other reliable sources of information, including the health care representative's personal knowledge of the patient's values, preferences and goals; and

(3) The patient's contemporaneous expressions, including nonverbal expressions.

d. If the instruction directive, in conjunction with other evidence of the patient's wishes, does not provide, in the exercise of reasonable judgment, clear direction as applied to the patient's medical condition and the treatment alternatives, the health care representative shall exercise reasonable discretion, in good faith, to effectuate the terms, intent, and spirit of the instruction directive and other evidence of the patient's wishes.

e. If the patient's wishes cannot be adequately determined, then the health care representative shall make a health care decision in the patient's best interests.

12. a. If the patient has executed an instruction directive but has not designated a health care representative, or if neither the designated health care representative or any alternate designee is able or available to serve, the instruction directive shall be legally operative. If the instruction directive provides clear and unambiguous guidance under the circumstances, it shall be honored in accordance with its specific terms by a legally appointed guardian, if any, family members, the attending physician, nurses, other health care professionals, health care institutions, and others acting on the patient's behalf.

b. If the instruction directive is, in the exercise of reasonable judgment, not specific to the patient's medical condition and the treatment alternatives, the attending physician, in consultation with a legally appointed guardian, if any, family members, or others acting on the patient's behalf, shall exercise reasonable judgment to effectuate the wishes of the patient, giving full weight to the terms, intent, and spirit of the instruction directive. Departure from the specific terms and provisions of the instruction directive shall be based upon clearly articulate factors not foreseen or contemplated by the instruction directive, including, but not limited to, the circumstances of the patient's medical condition.

c. Nothing in this act shall be construed to impair the legal force and effect of an instruction directive executed prior to the effective date of this act.

13. a. In addition to any rights and responsibilities recognized or imposed by, or pursuant to, this act, or any other law, a health care institution shall have the following rights and responsibilities:

(1) A health care institution shall adopt such policies and practices as are necessary to provide for routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive.

(2) A health care institution shall adopt such policies and practices as are necessary to provide appropriate informational materials concerning advance directives to all interested patients and their families and health care representatives, and to assist patients interested in discussing and executing an advance directive.

(3) A health care institution shall adopt such policies and practices as are necessary to educate patients and their families and health care representatives about the availability, benefits and burdens of rehabilitative treatment, therapy and services,

including but not limited to, family and social services, self-help and advocacy services, employment and community living, and use of assistive devices. A health care institution shall, in consultation with the attending physician, assure that such information is discussed with a patient and his health care representative and made a part of the decision making process set forth in section 11 of this act, as appropriate under the circumstances.

(4) In situations in which a transfer of care is necessary, including a transfer for the purpose of effectuating a patient's wishes regarding the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life, a health care institution shall, in consultation with the attending physician, take all reasonable steps to effect the appropriate, respectful and timely transfer of the patient to the care of an alternative health care professional or institution, as necessary, and shall assure that the patient is not abandoned or treated disrespectfully. In such circumstances, a health care institution shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

(5) A health care institution shall establish procedures and practices for dispute resolution, in accordance with section 14 of this act.

(6) A health care institution shall adopt such policies and practices as are necessary to inform physicians, nurses and other health care professionals of their rights and responsibilities under this act, to assure that such rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this act.

b. A private, religiously-affiliated health care institution may develop institutional policies and practices defining circumstances in which it will decline to participate in the withholding or withdrawing of specified life-sustaining treatments or artificially provided fluids and nutrition necessary to sustain life. Such policies and practices shall be written, and shall be properly communicated to patients and their families and health care representatives prior to or upon the patient's admission, or as soon after admission as is practicable.

If the institutional policies and practices appear to conflict with the legal rights of a patient wishing to forego health care, the health care institution shall attempt to resolve the conflict, and if a mutually satisfactory accommodation cannot be reached, shall take all reasonable steps to effect the appropriate, timely and respectful transfer of the patient to the care of another health care institution appropriate to the patient's needs, and shall assure that the patient is not abandoned or treated disrespectfully.

c. Nothing in this act shall be construed to require a health care institution to participate in the beginning, continuing, withholding or withdrawing of health care in a manner contrary to law or accepted medical standards.

14. a. In the event of disagreement among the patient, health care representative and attending physician concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive to the patient's course of treatment, the parties shall seek to resolve the disagreement by means of procedures and practices established by the health care institution, including but not limited to, consultation with an institutional ethics committee, or with a person designated by the health care institution for this purpose.

b. A health care professional involved in the patient's care, other than the attending physician, or an administrator of a health care institution may also invoke the dispute resolution process established by the health care institution to seek to resolve a disagreement concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive.

c. If disagreement cannot be reconciled through an institutional dispute resolution process, the parties may seek resolution in a court of competent jurisdiction.

15. a. Consistent with the terms of an advance directive and the provisions of this act, life-sustaining treatment, other than artificially provided fluids and nutrition necessary to sustain life, may be withheld or withdrawn from a patient in the following circumstances:

(1) When the life-sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician;

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician; or

(4) In the event none of the above circumstances applies, when the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the medical intervention to be withheld or withdrawn may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the medical intervention on an unwilling patient would be inhumane. In such cases prior to implementing a decision to withhold or withdraw life-sustaining treatment, the attending physician shall promptly seek

consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this act, or shall promptly seek approval of a public agency recognized by law for this purpose.

b. Nothing in this section shall be construed to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

c. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

16. a. Consistent with the explicit terms of an advance directive and the provisions of this act, artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient in the following circumstances:

(1) When the artificial provision of fluids and nutrition is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician; or

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician, and the likely risks and burdens associated with the least burdensome treatment modality likely to be effective may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the intervention on an unwilling patient would be inhumane. In such cases, prior to implementing a decision to withhold or withdraw artificially provided fluids and nutrition, the attending physician shall seek prompt consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this act, or shall promptly seek approval of a public agency recognized by law for this purpose.

b. Nothing in this section shall be construed to provide authorization for the health care representative, or any other individual acting pursuant to this act, to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to sustain life in the absence of explicit instructions to that effect in the patient's advance directive.

c. Nothing in this section shall be construed to impair the obligations of a physician, nurse or other health care professional to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

d. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

17. a. Consistent with the terms of an advance directive and the provisions of this act, the attending physician may issue a do not resuscitate order.

b. A do not resuscitate order shall be entered in writing in the patient's medical records prior to implementation of the order.

c. Nothing in this act shall be construed to impair any existing legal authority to issue a do not resuscitate order when the patient has not executed an advance directive.

18. a. An institutional or regional reviewing body which engages in prospective case consultation pursuant to paragraph (4) of subsection a. of section 15 and paragraph (3) of subsection a. of section 16 of this act shall advise the attending physician, patient and health care representative whether it believes that the withholding or withdrawal of the medical intervention under consideration would be in conformity with the requirements of this act, including without limitation: whether such action would be within the scope of the patient's advance directive; whether it may reasonably be judged that the likely risks and burdens associated with the medical intervention to be withheld or withdrawn outweigh its likely benefits; and whether it may reasonably be judged that imposition of the medical intervention on an unwilling patient would be inhumane. The attending physician, patient and health care representative shall also be advised of any other course of diagnosis or treatment recommended for consideration.

The advice of the institutional or regional reviewing body shall be documented in the patient's medical records.

b. The advice of an institutional or regional reviewing body acting in accordance with subsection a. of this section is not legally binding. A health care representative, attending physician, nurse, or other health care professional who believes the advice should not be followed may choose to:

(1) Pursue an alternative course of treatment for the patient. In this case, no immunity is conferred upon such actions by this act, and the individual is subject to civil and criminal liability and may be subject to discipline by the respective State licensing board for professional misconduct;

(2) Seek review by a public agency recognized by law for this purpose; or

(3) Seek review by a court of competent jurisdiction.

c. Nothing in this section shall preclude the transfer of the patient to another appropriate health care professional or health care institution. In this case the health care institution responsible for the patient's care shall assure that the health care professional or health care institution to which the patient is transferred is properly informed of the advice given by the institutional or regional reviewing body.

d. An institutional or regional reviewing body acting in accordance with subsection a. of this section shall conform to standards established by law and shall be subject to periodic accreditation and review under procedures established by law.

19. a. Nothing in this act shall be construed to alter, amend or revoke the rights and responsibilities under existing law of health care institutions not governed by the provisions of this act.

b. Nothing in this act shall be construed to preclude mental health institutions, facilities or agencies, or institutions, facilities or agencies for the developmentally disabled, from respecting an advance directive for health care executed by a patient or resident pursuant to this act.

c. The provisions of this act shall not be construed to require emergency personnel, including paid or volunteer fire fighters; paramedics; members of an ambulance team, rescue squad, or mobile intensive care unit; or emergency room personnel of a licensed health care institution, to withhold or withdraw emergency care in circumstances which do not afford reasonable opportunity for careful review and evaluation of an advance directive without endangering the life of the patient.

20. In accordance with the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.) the Department of Health shall establish rules and regulations necessary to carry out the provisions of this act. The rules and regulations shall require a health care institution to adopt policies and practices designed to:

a. Make routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive;

b. Provide appropriate informational materials concerning advance directives to all interested patients and their families and health care representatives, and to assist patients interested in discussing and executing an advance directive;

c. Educate patients and their families and health care representatives about the availability, benefits and burdens of rehabilitative treatment, therapy and services, as appropriate;

d. In cooperation with the respective State licensing boards, inform physicians, nurses, and other health care professionals of their rights and responsibilities under this act, to assure that the rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this act; and

e. Otherwise comply with the provisions of this act, including procedures for reporting to the department by health care institutions, and the gathering of such additional data as is reasonably necessary to oversee and evaluate the implementation of this act. The Department of Health shall seek to minimize the burdens of record-keeping imposed by the rules and regulations and shall seek to assure the appropriate confidentiality of patient records.

21. The Department of Health and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care established pursuant to P.L.1985, c.363 (C.52:9Y-1 et seq.), shall jointly evaluate the implementation of this act and report to the Governor and the Legislature, including recommendations for any changes deemed necessary, within five years from the effective date of this act.

22. a. A health care representative shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act:

(1) To carry out the terms of an advance directive; or

(2) To follow and implement the advice of an institutional or regional reviewing body acting in accordance with subsection a. of section 18 of this act.

b. A health care professional shall not be subject to criminal or civil liability or to discipline by the health care institution or the respective State licensing board for professional misconduct for any actions performed in good faith and in accordance with the provisions of this act and accepted professional standards:

(1) To carry out the terms of an advance directive; or

(2) To follow and implement the advice of an institutional or regional reviewing body acting in accordance with subsection a. of section 18 of this act.

c. A health care institution shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act to carry out the terms of an advance directive.

23. The absence of an advance directive shall create no presumption with respect to a patient's wishes regarding the provision, withholding or withdrawing of any form of health care. The provisions of this act do not apply to persons who have not executed an advance directive.

24. The execution of an advance directive pursuant to this act shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual because that individual has executed or has not executed an advance directive. The execution, or non-execution, of an advance directive shall not be made a condition of coverage under any policy of health insurance, life

insurance or annuity, or governmental benefits program.

25. An advance directive executed in another state in compliance with the laws of that state or the State of New Jersey is validly executed for purposes of this act. An advance directive executed in a foreign country in compliance with the laws of that country or the State of New Jersey, and not contrary to the public policy of this State, is validly executed for purposes of this act.

26. a. The withholding or withdrawing of life-sustaining treatment pursuant to section 15 of this act or of artificially provided fluids and nutrition necessary to sustain life pursuant to section 16 of this act, when performed in good faith, and in accordance with the terms of an advance directive and the provisions of this act, shall not constitute homicide, suicide, assisted suicide, or active euthanasia.

b. To the extent any of the provisions of this act are inconsistent with P.L.1971, c.373 (C.46:2B-8 et seq.) concerning the designation of a health care representative, the provisions of this act shall supersede those of P.L.1971, c.373 (C.46:2B-8 et seq.).

Durable powers of attorney for health care executed pursuant to P.L.1971, c.373 (C.46:2B-8 et seq.) prior to the effective date of this act shall have the same legal force and effect as if they had been executed in accordance with the provisions of this act.

c. Nothing in this act shall be construed to impair the rights of emancipated minors under existing law.

27. The Office of the Ombudsman for the Institutionalized Elderly shall adopt policies and practices necessary to comply with the requirements of P.L. , c. (C.) (now pending before the Legislature as this bill), and shall make a written statement of its obligations under that act available to the public.

28. The Office of the Public Guardian for Elderly Adults shall adopt policies and practices necessary to comply with the requirements of P.L. , c. (C.) (now pending before the Legislature as this bill), and shall make a written statement of its obligations under that act available to the public.

29. a. A health care professional who willfully fails to act in accordance with practices and procedures established by this act is subject to discipline for professional misconduct pursuant to P.L.1978, c.73 (C.45:1-21).

b. A health care institution that willfully fails to act in accordance with practices and procedures established by this act shall be subject to a fine of not more than $1,000 for each offense. For the purposes of this subsection, each violation shall constitute a separate offense. Penalties for violations of this act shall be recovered in a summary civil proceeding, brought in the name of the State in a court of competent jurisdiction pursuant to "the penalty enforcement law," N.J.S.2A:58-1 et seq.

c. The following acts constitute crimes:

(1) To willfully conceal, cancel, deface, obliterate or withhold personal knowledge of an advance directive or a modification or revocation thereof, without the declarant's consent, is a crime of the fourth degree.

(2) To falsify or forge an advance directive or a modification or revocation thereof of another individual is a crime of the fourth degree.

(3) To coerce or fraudulently induce the execution of an advance directive or a modification or revocation thereof is a crime of the fourth degree.

(4) To require or prohibit the execution of an advance directive or a modification or revocation thereof as a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program, or as a condition of the provision of health care is a crime of the fourth degree.

d. The sanctions provided in this section shall not be construed to repeal any sanctions applicable under other law.

30. This act shall take effect 180 days after the date of enactment.

STATEMENT

This bill establishes procedures for the execution of advance directives for health care. According to the bill, advance directives for health care may encompass both the designation of a health care representative, known as a proxy directive, and a statement of personal wishes regarding health care in the event of loss of decision making capacity, known as an instruction directive.

The purpose of this bill is to assure the respect for patients' previously expressed wishes when the capacity to participate actively in health care decision making has been lost or impaired. The bill establishes a procedure that facilitates and encourages a sound decision making process in which patients, their families and health care representatives, physicians, and other health care professionals are active participants. In addition, the bill provides the necessary and appropriate safeguards concerning the termination of life-sustaining treatment for incompetent patients.

The bill provides that:

(1) An advance directive becomes operative when it is transmitted to the attending physician or to the health care institution, and when the person is determined to lack decision making capacity.

(2) Once operative, the advance directive designating a health care representative confers upon that person the legal authority

to participate in the decision making process and to make health care decisions on the patient's behalf.

(3) In the absence of a designated health care representative an instruction directive, once operative, shall be respected and implemented.

(4) Life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient pursuant to an advance directive only in certain specified circumstances.

(5) An impaired patient's contemporaneously expressed wish that medically appropriate life sustaining treatment or artificially provided fluids and nutrition necessary to sustain life be provided shall take precedence over any contrary decision of the health care representative and any contrary statement in the patient's instruction directive.

(6) A declarant's directive to withhold or withdraw artificially provided fluids and nutrition must be explicitly stated in an advance directive.

(7) Health care professionals may decline to participate in the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life on the basis of sincerely held personal or professional convictions. In such cases the health care professional shall facilitate the appropriate, respectful and timely transfer of the patient's care.

(8) Private, religiously-affiliated health care institutions may adopt institutional policies and practices defining circumstances in which they will decline to participate in the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition necessary to sustain life.

(9) Individuals and institutions acting in good faith and in accordance with the provisions of this act to carry out the terms of an advance directive shall be immune from legal liability and from discipline for unprofessional conduct.

This bill is the result of the work of the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care, established pursuant to P.L.1985, c.363 (C.52:9Y-1 et seq.). This commission was established by the Legislature in 1985 to provide a comprehensive and scholarly examination of the legal and ethical dilemmas in the delivery of health care posed by modern advances in science and medicine.

CIVIL JUSTICE

Designated the "New Jersey Advance Directives for Health Care Act."

ASSEMBLY, No. 2957

STATE OF NEW JERSEY

INTRODUCED FEBRUARY 8, 1990

By Assemblymen KRONICK, KENNY, Roma
and Assemblywoman Ogden

AN ACT allowing an adult to execute a directive providing that life-sustaining procedures be withheld or withdrawn in the event of terminal illness, prescribing the form of the directive and providing for the means of revocation thereof.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. This act shall be known and may be cited as the "Natural Death Act."

2. As used in this act:

a. "Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

b. "Directive" means a written document voluntarily executed by the declarant in accordance with the requirements of section 3. The directive, or a copy of the directive, shall be made part of the patient's medical records.

c. "Life-sustaining procedure" means any medical procedure or intervention which utilizes mechanical or other artificial means to sustain, restore, or supplant a vital function, which, when applied to a qualified patient, would serve only to artificially prolong the moment of death and where, in the judgment of the attending physician, death is imminent whether or not the procedures are utilized. "Life-sustaining procedure" shall not include the administration of medication or the performance of any medical procedure deemed necessary to alleviate pain.

d. "Physician" means an individual licensed to practice medicine and surgery by the State Board of Medical Examiners.

e. "Qualified patient" means a patient diagnosed and certified in writing to be afflicted with a terminal condition by two physicians, one of whom shall be the attending physician, who have personally examined the patient.

f. "Terminal condition" means an incurable condition caused by injury, disease, or illness, which, regardless of the application of life-sustaining procedures, would, within reasonable medical judgment, produce death, and where the application of life-sustaining procedures serve only to postpone the moment of death of the patient.

3. Any adult person may execute a directive directing the withholding or withdrawal of life-sustaining procedures in the event of a terminal condition. The directive shall be executed

The declarant has been personally known to me and I believe him or her to be of sound mind. I am not related to the declarant by blood or marriage, nor would I be entitled to any portion of the declarant's estate on his decease, nor am I the attending physician of the declarant or an employee of the attending physician or a health facility in which the declarant is a patient. or a patient in the health care facility in which the declarant is patient, or any person who has a claim against any portion of the estate of the declarant upon his decease.

Witness........................
Witness........................

State of New Jersey
County of ....

Before me, the undersigned authority, on this day personally appeared.................................., and.............., known to me to be the declarant and witnesses whose names are subscribed to the foregoing instrument in their respective capacities, and, all of these persons being by me duly sworn, the declarant, ..., declared to me and to the witnesses in my presence that the instrument is his Directive to Physicians, and that he had willingly and voluntarily made and executed it as his free act and deed for the purpose therein expressed.

Declarant......................
Witness.......................
Witness........................

Subscribed and acknowledged before me by the Declarant, ..., and by the witnesses,......................., and ...., on this .... day of ...., 19...........

Notary Public in and for
........................, County, New Jersey.

4. a. A directive may be revoked at any time by the declarant, without regard to his mental state or competency, by any of the following methods:

(1) By being canceled, defaced, obliterated, burnt, torn, or otherwise destroyed by the declarant or by some person in his presence and by his direction;

(2) By a written revocation of the declarant expressing his intent to revoke signed and dated by the declarant. The revocation shall become effective only on communication to an attending physician by the declarant or by a person acting on behalf of the declarant or by mailing the revocation to an attending physician. An attending physician or his designee shall record in the patient's medical record the time and date when he received notification of the written revocation and shall enter the word "VOID" on each page of the copy of the directive in the patient's medical records; or

(3) By a verbal expression by the declarant of his intent to revoke the directive. The revocation shall become effective only

physician to be undertaken are in accord with the existing desires of the qualified patient and are communicated to the patient.

b. If the declarant was a qualified patient at least 14 days prior to executing or reexecuting the directive, the directive shall be conclusively presumed, unless revoked, to be the directions of the patient regarding the withholding or withdrawal of life-sustaining procedures. No physician, and no health professional acting under the direction of a physician, shall be criminally or civilly liable for failing to effectuate the directive of the qualified patient pursuant to this subsection. A failure by a physician to effectuate the directive of a qualified patient pursuant to this subsection may constitute unprofessional conduct if the physician refuses to make the necessary arrangements or fails to take the necessary steps to effect the transfer of the qualified patient to another physician who will effectuate the directive of the qualified patient.

c. If the declarant becomes a qualified patient subsequent to executing the directive, and has not subsequently reexecuted the directive, the attending physician may give weight to the directive as evidence of the patient's directions regarding the withholding or withdrawal of life-sustaining procedures and may consider other factors, such as information from the patient's family or the nature of the patient's illness, injury, or disease, in determining whether the totality of circumstances known to the attending physician justified effectuating the directive. No physician, and no health professional acting under the direction of a physician, shall be criminally or civilly liable for failing to effectuate the directive of the qualified patient pursuant to this subsection.

8. a. The withholding or withdrawal of life-sustaining procedures from a qualified patient in accordance with the provisions of this act shall not, for any purpose, constitute a suicide.

b. Making of a directive pursuant to section 3 of this act shall not restrict, inhibit, or impair in any manner the sale, procurement, or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of an existing policy of life insurance. No policy of life insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

c. No physician, health facility, or other health provider, and no health care service plan or insurer issuing insurance, may require any person to execute a directive as a condition for being insured for, or receiving, health care services nor may the execution or failure to execute a directive be considered in any way in establishing the premiums for insurance.

9. A person who purposely conceals, cancels, defaces, obliterates, or damages the directive of another without the

revocation with the intent to cause a withholding or withdrawal of life-sustaining procedures contrary to the wishes of the declarant and thereby causes life-sustaining procedures to the withheld or withdrawn, and death to thereby be hastened, would be subject to prosecution for criminal homicide.

JUDICIARY

The "Natural Death Act."

SENATE, No. 1208

STATE OF NEW JERSEY

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Senator AMBROSIO

AN ACT concerning the determination of death, enacting the New Jersey Declaration of Death Act and supplementing Title 26 of the Revised Statutes.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. a. This act shall be known and may be cited as the "New Jersey Declaration of Death Act."

b. The death of an individual shall be declared in accordance with the provisions of this act.

2. An individual who has sustained irreversible cessation of all circulatory and respiratory functions, as determined in accordance with currently accepted medical standards, shall be declared dead.

3. Subject to the standards, procedures and exemptions established in accordance with sections 4, 5, and 6 of this act, an individual whose circulatory and respiratory functions can be maintained solely by artificial means, and who has sustained irreversible cessation of all functions of the entire brain, including the brain stem, shall be declared dead.

4. a. A declaration of death upon the basis of neurological criteria pursuant to section 3 of this act shall be made by a licensed physician professionally qualified by specialty or expertise, in accordance with currently accepted medical standards and additional requirements, including appropriate confirmatory tests, as are provided pursuant to this act.

b. Subject to the provisions of this act, the Department of Health, jointly with the Board of Medical Examiners, shall adopt, and from time to time revise, regulations setting forth (1) requirements, by specialty or expertise, for physicians authorized to declare death upon the basis of neurological criteria; and (2) currently accepted medical standards, including criteria, tests and procedures, to govern declarations of death upon the basis of neurological criteria. The initial regulations shall be issued within 120 days of the enactment of this act.

c. If the individual to be declared dead upon the basis of neurological criteria is or may be an organ donor, the physician who makes the declaration that death has occurred shall not be the organ transplant surgeon, the attending physician of the organ recipient, nor otherwise an individual subject to a potentially significant conflict of interest relating to procedures for organ procurement.

d. If death is to be declared upon the basis of neurological criteria, the time of death shall be upon the conclusion of definitive clinical examinations and any confirmation necessary to determine the irreversible cessation of all functions of the entire brain, including the brain stem.

5. The death of an individual shall not be declared upon the basis of neurological criteria pursuant to sections 3 and 4 of this act when such a declaration would violate the personal religious beliefs or moral convictions of that individual and when that fact has been communicated to, or should, pursuant to the provisions of section 6, reasonably be known by, the licensed physician authorized to declare death. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of traditional cardio-respiratory criteria pursuant to section 2 of this act.

6. a. Prior to declaring an individual dead upon the basis of neurological criteria pursuant to sections 3 and 4 of this act, the licensed physician authorized to declare death, or another responsible person designated for that purpose, shall make reasonable efforts, in good faith, to determine whether this declaration would violate the personal religious beliefs or moral convictions of that individual. These efforts shall include, as is appropriate under the circumstances, review of available medical records, including advance directives for health care, and reasonable efforts to contact a person or persons, such as a family member, personal physician, religious leader, or friend, who maintained a close association with the individual sufficient to render that person knowledgeable concerning the nature and content of the individual's personal religious beliefs or moral convictions.

b. If a claim of exemption is reasonably advanced on the individual's behalf under this act, a physician or other health care provider responsible for the treatment and care of that individual shall:

(1) refrain from declaring the individual dead upon the basis of neurological criteria; and

(2) refrain from discontinuing, solely upon the basis of the individual's neurological status, mechanical or other artificial means employed to maintain the individual's circulatory or respiratory functions.

7. A licensed health care practitioner, hospital, or the health care provider who acts in good faith and in accordance with currently accepted medical standards to execute the provisions of this act and any rules, regulations issued by the Department of Health or the Board of Medical Examiners pursuant to this act, shall not be subject to criminal or civil liability or to discipline for unprofessional conduct with respect to those actions. These immunities shall extend to conduct in conformity with the

provisions of this act following enactment of this act but prior to its effective date.

8. Changes in pre-existing criteria for the declaration of death effectuated by the legal recognition of modern neurological criteria shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual solely because of that individual's personal religious beliefs or moral convictions regarding the application of neurological criteria for declaring death.

9. a. Pursuant to the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.) the Department of Health shall establish rules, regulations, policies and practices as may be necessary to collect annual reports from health care institutions, to gather additional data as is reasonably necessary, to oversee and evaluate the implementation of this act, including provisions relating to the exemption procedure established pursuant to sections 5 and 6 of this act. The department shall seek to minimize the burdens of record-keeping imposed by these rules, regulations, policies and practices, and shall seek to assure the appropriate confidentiality of patient records.

b. The Department of Health, the Board of Medical Examiners, and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care shall jointly evaluate the implementation of this act and report to the Legislature, including recommendations for any changes deemed necessary, within five years from the effective date of this act.

10. If any provision of this act or its application to any individual or circumstance is held invalid, the invalidity shall not affect other provisions or applications of this act which can be given effect without the invalid provision or application, and to this end the provisions of this act are severable.

11. This act shall take effect on the 180th day following the date of its enactment.

HEALTH

Enacts the "New Jersey Declaration of Death Act."

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ASSEMBLYWOMAN MARLENE LYNCH FORD (Chairman): Okay, I think we are going to get started now. Pat, will you call the roll please?

MS. NAGLE (Committee Aide): Assemblyman Stuhltrager?

ASSEMBLYMAN STUHLTRAGER: Here.

MS. NAGLE: Assemblyman--

ASSEMBLYWOMAN FORD: Excuse me, we are going to get started now. (referring to disturbance from audience)

MS. NAGLE: Assemblyman Shusted?

ASSEMBLYMAN SHUSTED: Here.

MS. NAGLE: Assemblyman Pelly?

ASSEMBLYMAN PELLY: Here.

MS. NAGLE: Assemblywoman Ford?

ASSEMBLYWOMAN FORD: Here.

Today we're holding a public hearing on the numerous bills that are in the Assembly and have been assigned to the Assembly Judiciary Committee, dealing with the issues of medical directives, -- what's commonly known as the living will issue -- and also the declaration of death issue.

I wanted to hold this on a long legislative day because I think that gives us the opportunity, without the pressure of any time constraints, to hear the many people who have expressed interest on these issues; to hear from the sponsors of the various legislation, as to the differences among the bills, and why perhaps one particular bill is more appropriate than another.

The first person I would like to hear from is Senator Ambrosio, who has really taken the lead on this issue in the Senate. So Senator, if you are ready with your testimony we'd like to take that right now.

SENATOR GABRIEL M. AMBROSIO: Thank you, Chairwoman, and members of the Committee. The series of bills that you are considering today literally deal with life and death. They're not easy issues. They're not issues that are Republican or Democratic issues. They're not liberal or conservative issues, but they are extremely important to the people of our State. They become increasingly more important each day as the exploding medical technological revolution literally allows us the sustain people between life and death, for an unlimited period of time.

There are two bills that are on your agenda today that I am the sponsor of. One is called the "Declaration of Death Act" in which, Assemblyman Kamin is the sponsor of an identical bill in the Assembly, and the second one is the "Advance Directives Bill" otherwise known as the living will legislation.

I really would just like to give you a very brief history of how these two bills got to your Committee. As you are aware-- I'm sure the Committee members are aware that New Jersey is one of the leading states in the nation in terms of our Supreme Court activity in dealing with death and dying issues; so much so that approximately 46 states have adopted living will legislation, primarily based upon the rationale and the decisions of the New Jersey Supreme Court.

New Jersey is one of the few remaining jurisdictions that does not have a living will bill in place. The Legislature, recognizing the need for us to clarify New Jersey policy in this area, in 1985 established the Bioethics Commission and directed this Commission to conduct a scholarly review of the laws of this State and to come up with suggested legislation to deal with these very very critical issues.

I served -- and I still serve -- as a member of that Commission, which is a bipartisan Commission made up of 27 representatives who have worked very very diligently over the past three years to come up with this proposed legislation.

You're going to hear from the Executive Director and the Chairman of the Commission who will give you an overview of the pains that were taken to delve into the questions that these two bills present to you. I'm not going to do that. I'm going to let others do that. I'd like to just discuss the two bills very briefly in terms of their content. The first one is the Declaration of Death Act, which recognizes -- what is already existing law in our State -- that death should be declared based upon neurological criteria, because a person whose brain has been totally destroyed is -- in all senses of the word -- dead and should be declared dead.

Our New Jersey Supreme Court has already acted in this area, in the Strechen case, in which total brain death has been recognized as a means and a criteria for declaring death. This is an important issue, because the technological capabilities that we have today gives us the ability to keep people's hearts and lungs alive after their brain has been destroyed. Therefore, it allows us to keep people alive and functioning on machines; a wish that most people do not want to have -- or at least want to make the choice as to whether or not that should happen to them. So, what the Declaration of Death Act does is, it recognizes what is already existing law and that is, that total brain death is a criteria for declaring a person dead.

What it does do however, is it goes further and sets up standards and criteria for how that death should be declared, and builds in a series of safeguards to insure that death is not declared prematurely. Before death is declared, based upon neurological criteria, the appropriate medical and confirmatory tests are performed and the person is in fact totally brain-dead. There is one area in this bill that I will put on the table as one that is still open to debate and discussion. The Bioethics Commission was made up of members that had different views on this issue. We heard testimony from various groups and organizations and various interested parties.

The bill that is before you, both Assemblyman Kamin's bill, and my bill, has a provision calling for a religious exception. That religious exception provision allows a person whose religion does not recognize total brain death or death by neurological criteria as a grounds or a method of declaring someone dead the right not to have the death declared until the standard method of determining death -- and that is when the cessation of all cardiopulmonary activity -- is arrived at. That religious exception is one that was built-in to the bill by the Bioethics Commission as a compromise that was arrived at after many many hours of debate and discussion.

I will tell you that it is not my personal view that the religious exception should be in this legislation. You're going to hear a lot of testimony. And I will tell you that if the Committee, after hearing all of that testimony, makes a judgment that the religious exception should not be included in this legislation, that I, as a sponsor of the Senate Bill, would accept that amendment. I know that Assemblyman Kamin will speak on this bill and he may or may not have a different position on that. So I will leave that for the discussion and for further deliberation of this Committee, as to whether they would release this bill without the religious exception. Just a note; that my personal view is that that exception should not be in the bill. On the Declaration of Death Act, that is really the only controversial provision about it, and I will say nothing more about that bill.

I would like to very briefly discuss the Advance Directives Bill. The State of New Jersey and the State of New York are the only two states that have established a Bioethics Commission to look into this area. We have conducted exhaustive hearings and debate on what type of legislation should be recommended to deal with the issue of advance directives. The legislation that you have before you is again, a compilation of a lot of thought and a lot of philosophy, and built-in, some additional compromises. I would just like to focus on the basic provisions of the bill and the issues that were compromised, that this Committee may wish to deal with.

The bill is rather straightforward in what it attempts to do. It recognizes the right of privacy, the right of self-determination of every individual, and the right of an individual to control his or her own health care decisions. What a living will does is, it recognizes that that right should not be lost once a person is no longer capable of communicating his or her wishes. It allows a person, while they are alive and competent to set forth in writing two things:

1) A person or persons that they wish to designate as a health care representative, to act in their place, should they no longer be capable of communicating their decisions.

2) Allows a person to set forth in advance what specific instructions they wish to have that health care representative or anyone else making those decisions implement.

One is called an advance directive or the appointment of a health care representative, and the other portion is called an advance directive or a direction in terms of what kind of decisions that person would like to have employed in their health care. The bill allows someone to appoint a health care representative and give instructions, or appoint a health care representative without instructions, or to leave instructions without appointing a health care representative. The bill then goes on further to deal with the technicalities and the requirements of how this should be done and how the advance directive should be implemented. I don't want to go into the specifics of that bill, beyond what I said, because you're going to hear a lot of testimony on it.

The one area that was a controversy in which the Bioethics Commission recommended a compromise dealt with the issues of artificially provided fluids and nutrition. The bill, as you have it, recognizes that artificial fluids and nutrition should be treated separate and apart from other forms of medical treatment. It provides that a living will can not be used to withhold or withdraw artificially provided fluids and nutrition unless the advance directive specifically allows that to happen. I will tell you that that was a compromise that was voted on by the Commission in a very close vote, agreed to have that compromise included in the bill. My personal view is that that is a compromise that I wish we hadn't made. I leave on the table the question as to whether or not that compromise should be eliminated by this Committee, and that the question of artificially provided fluids and nutrition -- in my judgment -- is another form of medical treatment and should not be singled out as a special form of medical treatment.

Again, you're going to hear testimony on both sides of that issue and somewhere down the line, this Committee will have to make a judgment as to whether or not my bill and the corresponding Assembly bill should be amended to eliminate artificial fluids and nutrition as a special form of medical treatment.

At this point, Madam Chairwoman, I will step back and let others speak on these bills. I thank you for considering these bills today.

ASSEMBLYWOMAN FORD: Thank you, Senator. Assemblyman Naples has joined us at the Committee table here.

ASSEMBLYMAN NAPLES: I can't vote though, right? (laughter)

ASSEMBLYWOMAN FORD: No, you can't. If you'd like to add anything, as one of the sponsors--

ASSEMBLYMAN NAPLES: Except to say that I agree with the Senator, that the inclusion of that which he talked about-- I think the artificial fluids and nutrition is just another contribution to life without dignity, in the final analysis. I'll speak on A-16, when it comes up.

ASSEMBLYWOMAN FORD: Assemblyman Kamin?

ASSEMBLYMAN RICHARD C. KAMIN: Thank you, Madam Chairman. Good morning members of the Committee. I think as my colleague, Senator Ambrosio recapped what has happened over the last four years with this Commission, an awful lot of work has been done. I'd like to comment on the two bills, one that I sponsor jointly with Senator Ambrosio, and the one that is sponsored -- the advance directives.

The religious exemption, I think is something that is open for debate. However, it was the compromise that did give the Commission a unanimous vote in support of the language, as you have it before you. There are some technical amendments, I believe as well, that would have to be considered and addressed by the Committee.

There is no question, in both cases, that there is a need for legislation. I think all of us can agree on that. But when it comes down to some very gut issues, some very closely held personal beliefs by people, then there are differences of opinion. Those differences of opinion are properly debated here and probably on the floor of the Legislature. We effectively, on the Commission, worked as a Committee of the whole. It's not easy to get unanimous opinions under any set of circumstances; certainly when everyone is participating each and every month and sometimes more often than that. Their subcommittees also meet each and every month on the merits of the two pieces of legislation.

I must disagree with some of the opinions expressed here so far on the second bill, on the advance directives. I do have a strongly held view that intravenous or artificial means of food and nutrition, to my mind, is non-debatable. It is a part of what should be always given to any patient in need. But again, that is going to be the decision of the Committee, in how these bills are handled. Since I am not a sponsor, I have little control on that one, but certainly there will be some debate here as well as on the floor of the house.

I thank the Committee for addressing these issues, and once again just echo, and say thank you to the members of the

Commission for their hard work over these many years. I'd like to single out Alan Weisbard, who was the former Executive Director, and Rob Olick, who is our current Executive Director, as well as Paul Armstrong, the current Chairman, and Dan O'Connell, who served as Chairman, and guided us through the passage of both of these bills, to get them this far out of the Commission.

We've worked very hard. The Commission itself has been functioning under a very strained economic situation, by having its budget cut for the last two to three years in a row, yet has been able to complete its business, and help you, and help the people of New Jersey with advancing, I think, a very needed agenda, which has been brought before you today. Thank you Madam Chairman.

ASSEMBLYWOMAN FORD: Thank you, Assemblyman. Okay, I have a number of people who notified the Committee in advance. I'm going to try to go through the list of those people, as they notified the Committee in advance of their interest in participating on this. The first person I have on my witness list is Dr. Russell McIntyre.

RUSSELL L. McINTYRE, Th.D.: Good morning.

ASSEMBLYWOMAN FORD: Good morning.

DR. McINTYRE: Thank you very much for the opportunity to testify. It is my pleasure to appear here as an official representative of the University of Medicine and Dentistry of New Jersey. And in that regard, you have received an official letter from Dr. Stanley Bergen, in support of both bills; S-1208, the New Jersey Declaration of Death Act, and the bill S-1211, the New Jersey Advance Directives for Health Care Act.

Let me enter into the record, Dr. Bergen's letter to you: "Dear Assemblywoman Ford: The University of Medicine and Dentistry of New Jersey, wishes to offer its support for two bills being considered by your Committee: namely, S-1208, the New Jersey Declaration of Death Act, and S-1211, the New Jersey Advance Directives for Health Care Act.

"This legislation provides a comprehensive approach to living wills and allows competent adults to specify in writing their medical treatment preferences. The measures also clarify the uncertainties regarding the legal status of advance directives and the obligations of health care professionals to honor such documents.

"The concept of brain death and advance directives are currently recognized by statute in 44 states and the District of Columbia. These measures will enhance New Jersey's reputation as a national leader in addressing legal and ethical dilemmas in the delivery of health care.

"Thank you for your consideration of these views. Sincerely, Stanley S. Bergen, Jr., M.D.; President, University of Medicine and Dentistry of New Jersey."

My name is Russell McIntyre. I am a Professor of Medical Ethics at the University of Medicine and Dentistry of New Jersey, the Robert Wood Johnson Medical School.

In 1976, when our State Supreme Court decided the landmark case of Karen Ann Quinlan, New Jersey, not only captured the national and international spotlight on these issues surrounding the care of the critically ill and dying patients, but it literally created that spotlight. There was no public discussion of these issues prior to Quinlan. In the intervening 14 years since Quinlan, these two concepts -- the declaration of death, based on medical defined neurological criteria, and the right of person to articulate for themselves, in written form, their advance directive for health care decisions -- have become the cornerstones for protecting the rights of us all.

Undoubtedly, you have heard that many of those who oppose these bills, claim that if a person signs a living will or advance directive, they will lose their rights forever. Nothing could be further from the truth. And for the elderly, who might be closer to death than most of us, it is a cruel and injurious lie. The Declaration of Death Act on neurological criteria -- brain death -- requires the complete cessation of electrical impulses in the total brain, including the brain stem, which automatically acts to control the mechanical body functions such as breathing, heartbeat, circulation of the blood, and peristalsis or movement of our bowels. When we have lost the electrical impulses in our brain stem, we are dead -- even if we are connected to a respirator -- and the machine is filling our deceased lungs with air.

The advanced directive legislation allows all of us to set forth specific directions, as to how we wish to be treated when we are dying, or have permanently lost the ability to benefit from the medical technology available to support our lives. It also allows us to appoint someone that we trust, to make decisions for us, if we are not competent.

But the bill before you is accommodative. Even those who reject the notion that patients ought to have this right, will have the right to say they want everything done to preserve their life for as long as possible. It is my professional and personal opinion that the citizens of New Jersey needs these bills in order to protect their wishes, and their own rights to decide. I strongly urge you to pass both S-1208, the New Jersey Declaration of Death Act, and S-1211, the New Jersey Advance Directive for Health Care Act.

Thank you.

ASSEMBLYWOMAN FORD: Thank you very much, Dr. McIntyre. Steele Chadwell?

STEELE R. CHADWELL, ESQ.: Good morning, Madam Chairwoman, Honorable Committee members, Senator Ambrosio, Assemblyman Kamin, and distinguished colleagues, and other members of the public. My name is Steele Chadwell. I am a member of Cooper, Perskie, April, Niedelman, Wazenheim, and Levenson; an Atlantic City law firm that represents a number of physicians, nurses, health care facilities, and others, who are involved in New Jersey's health care system as both providers, and consumers.

Before I became a member of the Health and Hospital Law Department of Cooper and Perskie, I served as General Counsel with the New Jersey Office of the Ombudsman for the Institutionalized Elderly, where I was deeply involved with the issue before your Committee today. That involvement was on a theoretical, policy level, and also on a practical, personal level with real patients, their families, and their caregivers.

It was my privilege to first think deeply about, and then brief, and argue the Peter and Jobes cases for the New Jersey Supreme Court. But more importantly, over the five-and-a-half years that I was with the State Ombudsman Office, it was my job to carefully and conscientiously carry out New Jersey law according to the Supreme Court's, Conroy and Peter guidelines. As a result, I saw the issue that is now before your Committee on a regular basis, and I saw it from a close-up, personal perspective. Given my experience, with what is always an intensely, emotional, and highly personal issue for anyone who faces it, I respectfully submit that you have a responsibility to act favorably on this bill -- and I am directing my remarks to Senate Bill No. 1211.

Simply put, this bill will help a lot of New Jerseyans who need help in circumstances where a living will or a medical power of attorney comes into play. Experience has shown me how much a bill like S-1211 is needed; not just on a professional level, or from a lawmaking perspective, but on the purely personal level. By that I mean that your Committee should release this bill for just one reason alone: Its enactment would help patients, their families, physicians, nurses, social workers, nursing homes, hospitals, and other health care facilities, and the many people who staff those facilities.

The bill's enactment would even help New Jersey attorneys involved in health care law, some of whom face bioethical dilemmas that recur again and again on a daily basis -- or regular basis. The bill would help these individuals by given clear, legal effect, to the patient's choice as expressed in a living will or medical power of attorney.

Many of our clients have told us that they strongly feel New Jersey lawmakers should give patients the legal right to make their own health care decisions. They believe that those health care choices should be respected under the law.

Now I know I part company here with a number of other lawyers, in the health and hospital law field, who said, they would like perhaps -- they would prefer a bill that uses different wording or is simpler in form. And in response, I can only say that we have needed a living will and medical power of attorney statute on the books in New Jersey even before the New Jersey Supreme Court encouraged the Legislature to enact one; first, speaking unanimously in its opinion in the Conroy case. The Conroy case was decided in January of 1985, and such a statute still has not been enacted.

If New Jersey had such a statute, but the statute needed to be amended after the experience of working with it for a period of time, New Jersey would at least have such a law on the books. And that law would then have already helped a great many New Jerseyans in health care decisions. New Jerseyans are going to be making and carrying out these decisions with or without laws that apply to the health care dilemmas facing them. These New Jerseyans have wanted your guidance and your help for some time. I respectfully submit that they deserve that legal guidance and that help, and that they deserve it now.

And unless you have a question or two, I'd just like to thank you very much, both personally and on behalf of Cooper, Perskie, and our clients.

ASSEMBLYWOMAN FORD: Thank you, Mr. Chadwell. Elmer Matthews, from the New Jersey Catholic Conference? By the way, if any member of the Committee has a question for anyone, just pipe up. That's fine. Thank you, Mr. Matthews.

ELMER M. MATTHEWS, ESQ.: Good morning Madam Chairman, and members of the Committee. For those of you who don't know who I am, my name is Elmer Matthews. I serve as General Counsel to the New Jersey Catholic Conference of Bishops.

I have appeared before legislative Committees over a few years now -- I have to admit -- on this specific subject. I can remember testifying before the Senate Judiciary Committee on Senator Russo's bill on advance directives, that spawned the creation of the Bioethics Commission; the Commission that I was privileged to serve on -- leave a preposition dangling -- for most of the life of the Commission, while these bills were being crafted and drafted. I had to resign from the Commission just before the actual vote on these final bills, because a question was raised as to whether in my professional capacity, as the General Counsel to the Catholic Conference, I could testify at legislative hearings such as this, because of my service on the Commission.

I enjoyed my work on the Commission. I believe that the persons who served on it were worthy, loyal, and dedicated people. But I'm afraid, as is always the case, where legislatively we talk about issues that are really moral, we sometimes find ourselves driven to create a morality by consensus, and unfortunately, that does not too often, serve the public good.

I don't want to take too much of your time, I know you have a lengthy witness list, but there are a few things that I feel bound to say to you and to report to you. There are two main bills as you have heard from the previous witnesses, that are the subject of this discussion, although your Committee listing calls for consideration of all of the bills touching on the subject that are before the Committee.

I will present to the Committee after the hearing, or after my testimony, a statement of the Conference that deals with all of the facets of these bills, but I won't presume upon your ears to talk about them all this morning.

I would like to start my testimony by talking initially about the termination of death bill -- the Declaration of Death Bill, Senate Bill No. 1208. By the terms of Senate Bill No. 1208: "An individual whose circulatory and respiratory functions can be maintained solely by artificial means and who has sustained an irreversible cessation of all functions in the entire brain including the brain stem, shall be declared dead." The New Jersey Catholic Conference supports this bill because it sets the standard for declaration of death as total brain-dead.

The bill recognizes that the actual determination of death is to be limited to those situations where all activity of the brain has ceased, including that of the brain stem. We believe it is more within the province of the Legislature and not the courts to set such a standard. We actually regard this measure as a protection of human life, because it set a standard as a protection for human life, which prevents a premature termination of any person's death. The bill draws the line, at life's end, where it should be drawn; not at some point earlier when health or consciousness is fading.

Interestingly enough, this bill is a product of the President's Commission, and was originally sponsored in this Legislature by Senator Russo. It passed both houses with the support of the New Jersey Catholic Conference about four or five years ago. That bill was vetoed by Governor Kean because of the lack of religious exemption as it pertained to Orthodox Judaic belief -- their understanding of death, according to the Talmud.

The Bioethics Commission, as Senator Ambrosio indicated, struggled long and hard with the problem of this exemption. And although we supported the bill originally, without the exemption, we now feel very very strongly in support of Orthodox Jewry, that this exemption should remain in the bill. We are talking about the practice of religion, of a segment of our society, and we strongly support the protection of the rights of the people of that sect.

The next item on the agenda: The New Jersey Advance Directives for Health Care Act, S-1211. In addressing S-1211, we think it is important to know the discussion I just had about the Declaration of Death Bill -- having been amended to accommodate the belief of certain religious persuasions. We submit that similar considerations ought to be given to the beliefs of other groups who find that S-1211, and similar legislation raises significant moral problems.

Now we recognize the travails, as I've have indicated, that have gone into the studies of the Bioethics Commission. Nevertheless, some of the provisions of this proposal raise significant moral problems, highlighting the need for serious debate on the purpose and risk of legislation on this subject. The Catholic Bishops feel a responsibility to contribute to this debate. They are concerned that legislation, which is ethically unsound, will further compromise the right to life, and respect for life in our society.

The provisions of the proposed act -- which we will discuss in this statement -- are so fundamentally inconsistent with our moral tradition, that if they remain in the bill in their present form, it is our opinion and our position that they will intrude on the religious and moral beliefs of the substantial majority of the citizens of this State.

The depravation of life sustaining treatment, of fluids, and nutrition, to patients who are not terminally ill, and the absence of a section dealing with the provision of these life sustaining measures to a pregnant woman, are the most notable examples of the deficiencies of this act in our judgment. Firmly embedded in our moral tradition is the principle that it is possible to kill innocent persons by acts of omission as well as acts of commission. Whenever the failure to provide appropriate medical treatment or adequate food and fluids carries out a proposal adopted by choice to end life, such an action is an act of killing by omission. In short, it is passive euthanasia. We absolutely reject euthanasia, by which we mean any affirmative or deliberate act or any deliberate omission intended to end life rather than to permit the natural process of dying.

The most critical provisions of the act involve those dealing with the decisions to forego life sustaining treatment and artificially provided fluids and nutrition. Every person has the duty to preserve his life, care for his own health, and seek necessary medical care from others, but these principles do not mean that all possible remedies must be used in all circumstances. One is not obliged to use "extraordinary" means; that is, means which offer no reasonable hope of benefit or which involve excessive hardship. Such decisions are complex and should be made by the patient in consultation with his or her family and physician, whenever possible.

Obviously, the easiest case is presented by a patient who is conscious and competent and has had the opportunity of full consultation with the medical staff and the family. The worst scenario would be to create an advance directive statute which might make the law a partner by virtue of an automatic triggering of an advance directive; in one case, in creating a life-threatening situation actually opposed to the best interests of a non-dying, unconscious, or incompetent patient; or secondly, in substituting a decision of the remote past, possibly not geared to the medical and personal realities of the present.

What can readily apply to the truly terminally ill does not, and should not, apply to non-dying patients, even those who are comatose or unconscious.

A basic point that must be kept in mind is that, for non-dying patients the discontinuance of fluids and nutrition does not simply allow the person to die from existing pathology. It initiates a new cause of death -- starvation or dehydration. Too often, lurking behind the decision to withdraw fluids and to withdraw nutrition is the assumption that the quality of life has so deteriorated that the patient would be better off dead. Such thinking opens the door to euthanasia.

Human life, however, is a basic good and the foundation of other goods, notable personal dignity, and human rights. All reasonable efforts should be made to sustain life, and thus, there should be a presumption in favor of providing fluids and nutrition to the unconscious, non-dying patient, unless or until the benefits of fluids and nutrition are clearly outweighed by a definite danger or burden to the patient, or are totally useless. Of and by itself, coma -- permanent of not -- does not justify direct termination of a patient's life. It must be emphasized that the judgment made here is not that the person's life is useless or excessively burdensome; rather, the judgment made is that the means used to preserve life are useless or excessively burdensome.

Thus, our position is -- and I've read it so that it can be explicitly stated -- that the withdrawal or withholding of life sustaining treatment or the artificial provision of fluids and nutrition should be limited to terminal cases arising from irreversible pathology from which death is imminent. Terminal illness would be defined -- by amendments that we proposed to these bills -- as, "an incurable or irreversible condition that, according to the best available medical judgment, will result in imminent death from an irreversible pathology."

The statement, which I will submit to you this morning, runs about 10 or 12 pages, and I have no intention of reading that to you. But I would like to emphasize that my clients -- the Catholic bishops of New Jersey -- are not opposed to an advance directive bill. We have supported advance directive bills around the country. We are opposed to certain provisions of this bill which fly in face of our theology, of our tradition, and the lives of the members of our church. And we cannot be more serious in advancing that argument to you.

I'd just like to touch upon a couple of other items, with respect to the language of the bill. You'll see that in my statement, I have specific amendments directed toward our criticisms of the bill.

In subsection e. on page two, we would propose to delete the reference to active euthanasia. It is our position, that we maintain that there should be no distinction between active and passive euthanasia. There should be no doubt, for example, that assisted suicide or omissions, creating a threat to life not otherwise at risk, would clearly constitute euthanasia.

On page three of our submission, we have added a definition of euthanasia, the absence of which, in this bill, is a serious deficiency. Euthanasia means: "Any affirmative or deliberate act or any deliberate omission intended to end life rather than to permit the natural process of dying." We have drawn this formulation from section 11 of the Florida law -- Life-Prolonging Procedure Act -- which is the citation to which we refer in our statement.

With respect to the definition of "terminal condition" -- which again we feel is a glaring of error in the proposed legislation -- we feel that the current definition is defective. The definition should not say what it is not, or should not be based on preconditions or periods of time. We propose the following: "Terminal illness means an incurable or irreversible condition that, according to the best available medical judgment," -- as indicated early -- "will result in imminent death from an irreversible pathology."

Interestingly enough, if you refer to one of the other bills on your list before you this morning, A-1341 -- the so-called Right to Die Act -- under the definition of terminal illness in that bill, actually a person who has diabetes -- and did not want to consider treatment -- could be considered terminally ill under that definition. It sounds ridiculous, and I really believe it is ridiculous, but I think we should firm that up.

Finally, but by no means less important, I'd like to turn to the subject -- the area where we recognize a professional conscience in an institution. We enthusiastically support the provision in section 10., which protects the professional conscience, and the provision in section 13., which protects the conscience of religiously affiliated health care institutions.

Our amendment would delete "religiously affiliated" so that that provision would apply to all private health care institutions. The failure to include all institutions ignores the fact that the moral values -- that is the Hippocratic oath; respect for life -- on which professional conscience is based also may shape the institutional conscience of the institution in which a medical practitioner practice.

We submit that there is ample legal authority for applying institutional conscience to nonreligiously affiliated hospitals. The Bioethics Commission's proposed legislation on determination of death, recognizes not only a religious exemption but also one grounded in personal moral convictions. Our Supreme Court in Jobes, left open the possibility that an institution's policy not to participate in the withdrawal or withholding of artificial feeding, if communicated in advance to the patient would be upheld.

Throughout the Act is the notion that patient choice is paramount. What is neglected is the equally viable principle that a hospital or a health care institution should not be compelled to violate its moral and ethical principles. If a private, nonreligiously affiliated health care institution notifies a patient that its policy prohibits the withdrawal or withholding of life sustaining treatment and artificially provided fluids and nutrition, such a policy should be honored so that the institution can be faithful to its own code of ethics.

I appreciate the opportunity to appear before you this morning. This is an issue for which I've indicated to you that I have expressed the concern of my clients to the Legislature over the past, probably, ten years. We are at a point of a viable breakthrough on this issue. I would exhort you to consider all of the comments that are made this morning. I would also exhort you to consider the amendments which we've proposed, which we think will make this a viable act; that will work for all of the people, and not for some of the people that unfortunately might have driven the decisions of the Bioethics Commission. I do not fault the zeal, or their dedication, but it's very very simple running through the votes of the Commission that there was that base within the Commission.

So, without further infliction on your time, I'd like to thank you for your attention, and I'll be happy to answer any questions, now or in the future. Thank you.

ASSEMBLYWOMAN FORD: Thank you, Mr. Matthews. The next people we have on the list, I assume are coming up as a group, are the members of the Bioethics Commission. Mr. Armstrong, Mr. Olick--

ROBERT S. OLICK, ESQ.: Yes.

ASSEMBLYWOMAN FORD: Rabbi Blech, and Anne Perone. Do you want to testify together or separately?

PAUL W. ARMSTRONG, ESQ.: Oh no, Chairwoman, no. We have separate testimony.

ASSEMBLYWOMAN FORD: Okay. Great.

MR. ARMSTRONG: Mr. Olick and I will be presenting the Commission's view. Some are individual members of the Commission. They are not speaking for the Commission.

ASSEMBLYWOMAN FORD: Okay.

MR. ARMSTRONG: Would it be all right to proceed?

ASSEMBLYWOMAN FORD: Sure.

MR. ARMSTRONG: Good morning, Chairwoman Ford, and members of the Committee. I want to thank you for the opportunity to present testimony on behalf of the New Jersey Bioethics Commission, and allow me, of course, to introduce Robert Olick, who is our Executive Director.

In preface, on behalf of the 27 members who now serve on the Commission, I wish to thank you and your colleagues in the Assembly for the creation of, and the privilege to serve on, the New Jersey Bioethics Committee.

As you know, there are only two such special commissions in existence in the nation. One was created as an executive committee, by Governor Cuomo in New York -- in our sister state of New York -- and our own, here in New Jersey, created by you, the members of the Legislature.

Appreciating the great number of New Jersey citizens who join us today to offer testimony, what I would like to do, Madam Chairwoman, is simply to highlight the in-depth prepared written remarks, which we have provided to each member of the Judiciary Committee. If I could, please look to the packet prepared for you by the Commission, and in it you will find the following:

1) It is the Commission's position paper and the extensive and ongoing list of supporters for the New Jersey Advance Directive for Health Care Act. As a matter of fact, as Dr. McIntyre pointed out, there are two additions: Dr. Bergen, from UMDNJ, as well as the Mercer County Medical Society.

2) You will see the Commission's position paper, and list of supporters for the New Jersey Declaration of Death Act which is before you.

3) The written submission of our public hearing testimony today, and a list of the present and past members of the Bioethics Commission.

4) The advance directive forms and informational brochures, prepared and presented to you and to a number of citizens throughout the State of New Jersey.

Chairwoman Ford, if I could, the record simply must reflect our gratitude to Assemblyman Kamin, Senator Ambrosio, Assemblyman Stuhltrager, Karl Weidel, Thomas Deverin, David Schwartz, Stephanie Bush, and to you, Gerard Naples, for your support, and all of whom have served this Commission with distinction on behalf of you and your colleagues in the Assembly.

Both the Advance Directives Act and the Declaration of Death Act are the product of a process marked by extensive public hearings, testimony, and open, forthright, and respectful discussions among the diverse 27 members of the Bioethics Commission. This process has lead to scholarly, detailed, and -- I would submit -- a nationally acclaimed report entitled "Problems and Approaches in Health Care Decisionmaking: The New Jersey Experience," which has been provided to all members of the Legislature.

The Advance Directive Act and Declaration of Death Act are also the important product of close cooperation among your colleagues in the Senate; again, particularly Senator Ambrosio, the Office of Legislative Services, and the Bioethics Commission itself.

This has been a special room, as I'm sure some of you recall. We here in New Jersey have come a long way since "Time" magazine published the cover -- oh I'm sorry -- "Newsweek" published this cover in November of 1975 (witness displays cover of magazine). You will recall that this is actually the conference room of the New Jersey Supreme Court. Through that hallway we argued the case of Karen Ann Quinlan; a number of us were privileged to do that, on behalf of the family.

In fact, we have only to look to a current cover of "Time" magazine, -- spring of this year, -- to be reminded that New Jersey remains a national leader in bioethics. These two legislative proposals are clearly now a part of the rich tradition of New Jersey's leadership in this area. Not only that, the New Jersey Supreme Court has addressed the specific issues that you deliberate today, but now that the United States Supreme Court -- in the Curan case -- has spoken, the role of the State Legislature has become evermore important and critical in this area.

I know that you know, 49 of our sister states now recognize neurological criteria in the determination of human death. The New Jersey Declaration of Death Act would be the first in the nation to specifically recognize and protect religious and ethical exceptions to such criteria. This principle was so important to the Commission that it overwhelmingly voted to accord these protections to New Jersey citizens.

I know that you know as well, that 45 of our sister states and the District of Columbia now have statutorily created, so-called living wills, as you pointed out Madam Chairwoman, and durable powers of attorney for health care laws. The proposed New Jersey Advance Directives for Health Care Act goes beyond most existing legislation in other states in a number of important respects, including its applicability to a broad range of health care decisions; its commitment to a shared commitment making process among patients, families, health care representatives, physicians, and other health care professionals; its recognition, fundamentally, that patients should be permitted as a matter of constitutional law, to request the continued provision of life sustaining measures as well as the foregoing of life sustaining measures; its respect for the individual conscience of health care professionals; and its readiness to confront and address the appropriate role of societal interest and concerns regarding the foregoing of life sustaining measures.

In our view, this bill is a product of extensive and open public deliberations. The proposed legislation sets a new standard in this difficult area, enhancing, I believe, New Jersey's reputation as a national leader in addressing legal and ethical dilemmas in the delivery of health care.

As with your colleagues in the Senate, we have looked forward to working closely with you, the staff, the Judiciary Committee, the Assembly, and the Office of Legislative Services, as the bills proceed through the legislative process.

Again, Chairman Ford, and members of the Committee, the Bioethics Commission thanks you for the opportunity and your continuing support, and stands ready to serve the citizens of New Jersey. If there are any questions, we can direct them through the staff, or if there are any questions we'll be happy to entertain them today.

ASSEMBLYWOMAN FORD: Thank you.

MR. ARMSTRONG: Thank you very much then.

ASSEMBLYMAN SHUSTED: Madam Chairman?

ASSEMBLYWOMAN FORD: Assemblyman Shusted?

ASSEMBLYMAN SHUSTED: Mr. Armstrong, how many members-- You said there were 27 members of the Commission?

MR. ARMSTRONG: That's correct.

ASSEMBLYMAN SHUSTED: Were there any dissenting votes cast by any member of the Commission as far as these bills are concerned?

MR. ARMSTRONG: On specific issues-- There are a host of issues -- as far as the religious exception to the neurological criteria for brain death-- Yes. I believe one of our members, Patricia Murphy, who represents the Nurses Association-- Although the Nurses Association supports it, Patricia did cast a vote against including the religious exception to neurological criteria for brain-dead.

Rob, are you aware of any others on that particular bill?

MR. OLICK: Yes. There was a statement submitted by Elmer Matthews, regarding the particular points on the authority of -- he's here, he can speak for himself -- the amendment. The statement is reproduced in our report, and the point was that the original proposal from the Commission authorized the Department of Health and the State Board of Medical Examiners to proceed in promulgating criteria, test, and procedures, for the determination of brain death; to proceed either by regulation or by interpretive guidelines.

The recommendation of Elmer Matthews was that they not be authorized to proceed by interpretive guidelines, and that amendment, in fact, was made on the Senate side.

ASSEMBLYMAN SHUSTED: Well, maybe I didn't state my question correctly. The average position paper of the Commission--

MR. OLICK: Yes.

ASSEMBLYMAN SHUSTED: --on both of these bills, which would leave me to believe that the Commission supports both bills-- My question is, were there any members -- any one of the 27, or any more than one of the 27 members who did not accept, or did not endorse the position paper?

MR. ARMSTRONG: In the whole, they endorsed the legislation, with exceptions from it. In particular, there are a number of commissioners who objected to the election to forego artificially provided nutrition and hydration. That has been reproduced, specifically -- the votes and the positions of all Commission members -- in this report, which we provided to all members of the Assembly.

I'm sorry. On the bills themselves, they're unanimous with the one dissenting vote on them. There are specific filings by various members of the Commission on particular issues, but in the main, they voted for the presentation of these bills to the Senate and to you.

ASSEMBLYMAN SHUSTED: So if you had 27 votes taken, it was 27 to zero, when each bill was at--

MR. ARMSTRONG: I'm sorry--

MR. OLICK: There was also a minority report submitted by five members of the Commission at the end of 1988, which is reproduced in this report, and that was on the Advance Directives for Health Care Act.

ASSEMBLYMAN SHUSTED: Did the Commission take a vote as to its position on each bill?

MR. OLICK: Yes.

MR. ARMSTRONG: Yes.

ASSEMBLYMAN SHUSTED: And was that vote 27-0?

MR. ARMSTRONG: Twenty-two to five, and 26-1.

ASSEMBLYMAN SHUSTED: And the 26-1, which bill?

MR. ARMSTRONG: On the brain death, with the religious exception. Twenty-two to five on the Advance Directives for Health Care.

ASSEMBLYMAN SHUSTED: Thank you.

MR. ARMSTRONG: Thanks very much.

MR. OLICK: Thank you.

ASSEMBLYWOMAN FORD: Rabbi Blech?

RABBI SAMUEL BLECH: My name is Rabbi Samuel Blech. I am a clergyman from the central section of our State, and serve as a chaplain in a 240-bed nursing facility. I'm a Professor of Biblical law, in Biomedical Ethics, in a Theological Seminary, and the Governor's appointee to the

Bioethics Commission, of which I am a member of the Executive Committee, and I Chair the Task Force on Protecting the Vulnerable.

Thank you for the opportunity to testify on behalf of the legislative issues being studied today.

The New Jersey's Declaration of Death Act, as you well know, is a result of over two years of intensive deliberation and debate. It is an historic piece of legislation that all who shared in its creation, sensed throughout this experience. It is no doubt also flawed, as any other important legislation might be, but it is, nevertheless, the product of a sincere effort on the part of a group of dedicated men and women of which I am proud to have been numbered.

The vast majority of states across the country have legislated neurological criteria or "brain death" -- as it is properly referred to -- as acceptable for the pronouncement of death by medical professionals. We, in New Jersey, have an opportunity to once more, put into place a piece of legislation which will not only be a copycat version, but rather serve as a thoughtful and insightful model for others to follow.

It is particularly significant in my opinion, to note that we in New Jersey were wise in allowing ourselves to wait -- under great pressure -- until the dust had settled, so that we could gain from the experience of the other states, which had already legislated their attempts in this direction. The temptation to quickly follow suit and avoid the appearance of dragging our feet, especially in light of our State's role as a pacesetter in the entire nation, was enormous, and we felt it. We felt it in our deliberations. It did allow, however, that a extremely diverse group of scholarly people were able to carve out a singular document, which stands out as a model of sensitivity and concern for all of the citizens of our State, again establishing a precedent to be emulated by others.

The personal or religious exemption which not only allows for the acceptance of a new criteria in the pronouncement of death, but continues to recognize the traditional format as well, is probably the element that invites the most attention.

We, as a group, in our deliberations, came to the conclusion that to accept new criteria is to broaden the concept rather than to reject the traditional mode by which many cultures declare their dead, and has been the case for thousands of years. We ought not deny those who have a personal or religious reason for interpreting death -- as their forebears did -- their rights of protection under the law. This approach runs much closer to the ever greater recognition of individual autonomy in medical decision making.

I'd like just for a moment to address two of the principle concerns: Ideological concerns from the segment of the medical community -- and I'm confident that it is a small segment -- that continued acceptance of traditional criteria perpetuates an archaic concept. I think that runs hollow, and must at best be viewed at being cavalier and shallow in its depth.

Health care providers, as well as lawyers and clergyman, for that matter, are, and always should be, open to considerably more than the narrow confines of their own disciplines. They, and professionals in other fields as well, cannot claim infallibility, and they possess the shortcomings common to all of us. We, in the Commission, were mindful of the need to recognize this truth and seek to earn the trust and confidence of our citizens by allowing for free expression of personal preferences rather than dictate.

The additional concerns of those involved in transplant work -- that maintaining traditional criteria might undermine the acceptance of neurological criteria in the declaration of death, is, in my opinion, also unfounded; quite the opposite. Insisting on the dramatic departure from deeply held principles -- which has spanned the millennium of the history of man must be by its very nature that which foments distrust, allowing for a gradual awareness through educational processes, and a tolerance for diversity -- only contributes to credibility and acceptance.

As to the further concern -- that our health care system cannot easily tolerate a two-track approach for the sake of uniformity, and imposes undue stress on caregivers -- I think that this as well, is probably a misinterpretation of the issue, and I must draw a parallel if you'll forgive me, from Roe v. Wade. The legal acceptance of abortion on demand may present a picture in our obstetric units of a struggle to preserve the life of a prematurely born infant in one bed, while ironically dispatching another fetus in a second bed. This duality, it appears to me, is much more striking and emotionally demanding of our health caregivers, and the health care community has not viewed this as being inconsistent.

I think waiting the short time, rarely more than 24 to 48 hours, between neurological criteria and traditional standards in the declaration of death, is hardly an unreasonably nor burdensome imposition on the system and its practitioners. I think that this has perhaps not been articulated clearly enough because of the lay confusion between brain death -- which this bill addresses -- and the so-called pvs -- permanent vegetative state -- which this bill does not address.

The off painted picture of doctor, nurse, and family, fretting over a brain-dead patient for years, utilizing valuable medical services and exhausting resources, is a misrepresentation calculated to elicit a highly emotional, yet unjustifiable response. Many of us has been lead to believe that brain-dead people linger for weeks and months attached to machines which maintain their vital functions. This is scientifically untrue and a distortion of fact. The systems of a brain-dead person deteriorate rapidly despite all mechanical support, meaning that the time until traditional criteria for death sets in is relatively short.

The legislation before you, therefore, finds that allowing for personal autonomy does not unduly infringe nor burden the health care system, and respectfully allows for the free expression of all citizens of our State. We wish to encourage the endorsement of your Committee, Madam Chairwoman, and ultimately its release and passage on the floor.

If I may just burden you for one more moment, I had noticed something which I found disturbing and I think it sets a fabric upon which this is painted, in terms of the care -- the great attention that we must bring to these issues. Two Nobel laureates have been quoted as to their attitudes in the issues that concern us today. James Watson said the following: "If a child were not declared alive until three days after birth, then all parents could be allowed the choice only a few are given under the present system. The doctor could allow the child to die if the parents so choose and save a lot of misery and suffering. I believe this view is the only rational, compassionate attitude to have." This is from a Nobel laureate. And the second quote which I feel is important, too, is one by Francis Crick: "No newborn infant should be declared human until it has passed certain tests regarding its genetic endowment, and that if it fails these test, it forfeits the right to live."

I think it sets a certain tone about the seriousness of the issues that confront us, and it reminds us of the awesome responsibility that we have. And I think it lauds us. It expresses its appreciation for the fact that we in New Jersey have waited until the vast majority of our sister states have taken the initiative, to make sure that we are doing that which is correct.

Thank you for allowing me to share my thoughts with you, and may our labors be blessed with success.

ASSEMBLYWOMAN FORD: Thank you, Rabbi.

ASSEMBLYMAN NAPLES: Thank you.

ASSEMBLYWOMAN FORD: Is Anne Perone here?

ANNE M. PERONE, ESQ.: My name is Ann Perone. I'm an attorney. I'm also a member of the Commission for the Bioethics, in New Jersey. I was appointed by Chuck Hardwick. Unfortunately, I wasn't privy to the vote, when they approved in the Commission, the Advance Directives Act and also the Declaration of Death Act. I do dissent from approving both of these bills, and I regret today that both of these bills are being considered together because I think both of them warrant a full day's hearing at least, because of the confusion between the two bills.

As the Rabbi just said, people confuse brain death with persistent vegetative state. They seem to think that a person who is in a coma is brain-dead, and so on. There are two separate issues, and I want to address both of them: The first one I will speak to is the brain death issue. I have only my own notes but I will, after this, edit them and hopefully send them to the Committee.

As I said before, it's unfortunate that the living will bill -- the Advance Directives Bill -- and the Declaration of Death Bill are both being considered today, because they are confusing. My personal position is very similar to other people who spoke here before me. When a person is imminently dying, it is ethical to stop treatment, and it is ethical not to force them to continue living. Nobody is for that. We have had people die through the centuries with natural, loving, appropriate nursing and medical care.

But these two bills I see as dangerous and unnecessary, for various reasons. Addressing the issue of the patient who has been declared dead: First of all, they lose all of their rights under these bills. They're losing their rights because the physician in charge is deciding whether that person shall have continued medical care.

Now the last time this issue was brought before this Committee -- not this Committee but the Senate Committee -- a fellow attorney from Toms River came forth and testified, and he was very disturbed. His father who was in his early '70s, and who had been a musician all of his life, was declared brain-dead in a hospital down in Ocean County. This attorney, who had all the powers of the law behind him -- and he also was quite knowledgeable on the issue -- was asking the doctors who was treating his father for the test. He looked at the test, and there was electrical activity on an EEG. In order to assist his father, he put a hearing set on his ears so that he could promote his father listening to music, because the father was a professional musician. His father responded to the music. He was making gestures with his mouth, and his eyes, and so on. However, the physician, a neurologist who examined him said, "No, he's brain-dead."

Now the reason that this is dangerous is because studies have shown that physicians and nurses -- 65% of them -- aren't properly informed about the criteria for brain death. Now this attorney who testified before the Senate Committee -- similar to yourselves -- months ago, said that, his father -- although he was declared brain-dead-- And if he really were, he would have died within five to seven days. His father-- The doctor removed food and water from him, and all he permitted him to have was water and glucose, which wasn't sufficient for his brain to even kick back. You need nutrition for your brain.

So after 28 days, his father is wasting away on a diet of water and glucose. The father's system eventually did fail, but he was not brain-dead, because the son looked at the electrical records. Now what is the danger of this particular bill? The other thing too is that this attorney tried to get other physicians from other hospitals to come in and look at his father, but it was next to impossible to get any other neurologist to come in once one or two physicians in the hospital had made the determination. So he was very distraught, and he's still distraught to this day.

The problem with this bill is it gives immunity to the physicians. Now this attorney still is contemplating bringing a lawsuit for the neglect of his father, causing his death by not feeding him, having nothing to do with the brain death. That's one of the points. The second point is the concept of brain death is still not understood, as I said before. And this is not my opinion. This is an opinion of various studies, and I'll mention a few of them.

There was a study in 1989 by Dr. Peter Black and David Torres -- two doctors of the Harvard Medical School -- entitled "Pediatric Brain Death and Organ Tissue Retrieval." Black and Torres reported on 15 pediatric patients who were declared brain-dead. The criteria included an apnea test. That means the child is monitored and then when a certain pressure is reached-- Well, you'll see it from the report. The criteria include that the ventilator is disconnected to see if the patient breathes on its own. The patient will not breath on its own. The patient will not breath on its own until the CO_2 pressure reaches a certain point. Now in this particular case, the accepted medical criteria used by these two doctors from Harvard stated that if the CO_2 pressure at the end of the test exceed 50 millimeters of mercury, apnea has been adequately demonstrated. So their cutoff line was 50 millimeters, without the ventilator.

The fallacy of this accepted criteria used in the determination of death -- for these 15 patients -- was recently shown in the "New England Journal of Medicine," in March of 1988. A baby in Canada was declared brain-dead, and when he didn't breath on his own, after disconnection of the ventilator, his CO_2 pressure reached 54 millimeters -- which was even higher than the Harvard test -- at his declaration of death. The baby was transferred to the U.S. for consideration as a heart donor, and the excepted criteria in the particular hospital that he went to was for CO_2 pressure of 60. When the pressure reached 59 -- as they were waiting to let hit 60 -- the child breathed on his own.

If internationally known brain experts, such as Dr. Black and Dr. Torres used criteria that are evidently suspect or incorrect, what guarantee do we, the New Jersey citizens, have that the Department of Health will adopt the proper standard? We have three different standards here. There were 50 in the Harvard study, 54 in Canada, and 60 in this particular hospital. And the child was not brain-dead. He could breath on his own.

The test that they use in a hospital to determine if someone is brain-dead, is really basically clinical bedside examination. They put ice water in the ear, to see if the eyes goes back and forth. They put a swab of cotton across the eye, to see if they blink. They put a gag down their throat, to see if they gag. And if these few test that do-- They shine a light in the eyeball, to see if it opens and contracts.

Just with clinical standards, if our Department of Health decides that's going to be the standard, many many people are going to die in the State of New Jersey because there are drugs that will mask brain death, and this is a drug culture. There are people who may have taken a tranquilizer, and they're in a car accident and the tranquilizer will mask the response of the eyes, the throat, and so on, and this is proven in many cases.

We've submitted this documentation to the Commission. The New Jersey Bioethics Commission invited three medical experts to report about brain death. All three of these experts suggested that an EEG not be required. Now an EEG is a device which measures electrical stimulation when a person is in a living state. But it really just measures the outside of the brain. It doesn't even measure the whole brain. But the EEG-- They recommended that it should not even be required. As a matter of fact, in the case of Strachan in New Jersey -- this was a young man who had a head injury -- the emergency room declared him brain-dead within 20 minutes of his arrival to the hospital. They did not perform an EEG. They were just doing it on clinical criteria.

This has happened across the country, because already in the country there's an Anatomical Gift Act -- Donation of Organ Act -- and those criteria are there already. We do not need a brain death statute in New Jersey because federally, there is a law which has criteria at least established into it -- waiting 24 hours, and so on, and performing multiple tests.

This particular legislation as proposed, is asking the Legislature to deny their responsibility by delegating the authority of the guidelines to the Department of Health. And I must tell you, I learned recently that-- As part of my work, I do study other organizations that are promoting this kind of thing. There are organizations that -- their ethics believe that this is the proper thing to do.

One of the organizations is the Concern for Dying, and Society for the Right to Die, in New York. One of the people, who was a board member for the Concern for Dying, for many years -- more than 10 years -- was an Assistant Commissioner of the Department of Health in New Jersey, before his death. This particular person was in a very high position in New Jersey, for making rules and regulations, yet he was a board member of the Right to Die Society/the Euthanasia Society. When you give over your responsibility as legislators, you don't know who is going to be making the rules and regulations.

And basically, I feel that it is your responsibility not to give it over to people who may have their own political agenda. The point is, we vote for you; we elect you. The people in agencies are not voted for, or elected, and their backgrounds are not investigated by the public and the public's not aware.

This advise, by the way, of these three physicians who appeared before the Bioethics Commission is, it is horrendous that a EEG should not be performed because a blood clot in the brain could prevent a person from emanating all of the systems. They would give all of the symtoms of being brain-dead, in other words, not responding to any of those clinical examinations. A EEG would show that there is electrical activity in the brain, but these guidelines don't call for it.

There are also situations when patients -- especially if they're going to have a tube stuck down their throat -- are given certain medications. These medications has been proven to paralyze people at certain times. So you could have this medication, purely to assist you in emergency situations and then be totally paralyzed and appear brain-dead when you are not. The horror of this kind of--

ASSEMBLYMAN NAPLES: Excuse me.

MS. PERONE: The horror of this kind of situation is that you can be totally conscious and be what they call in a "locked-in state," either by the injury or a medication, be totally aware and yet not be able to communicate, even by blinking your eye. People can declare you brain-dead and you can be totally aware; put you into an operating room and have your organs removed. The horror, too, of when your organs are removed is that you are not anesthetized. You are paralyzed, so that your body does not move. The body thrashes around when organs are being removed. The body is paralyzed but not anesthetized, so there is the possibility a person could be in a locked-in state, be totally aware, and have their bodily organs removed because they've been declared brain-dead.

ASSEMBLYMAN PELLY: What is the name of that drug that causes that horrible--

MS. PERONE: That's (indiscernible). I can't say it but I can spell it.

ASSEMBLYMAN PELLY: Succinylcholine?

MS. PERONE: Succinylcholine, yes. And there is-- I've seen films of people, and testimony of people who were declared brain-dead and couldn't move a muscle for hours, until that drug wore off. But again, as the Rabbi said, time is of the essence. Why do we have to just give blanket regulations or punt over the regulations, when a person who is brain-dead is going to die within five to seven days anyway?

There is a Dr. Gian-Emilo Chatrian, writing in the 1986 medical textbook, "Electro Diagnosis Clinical Neurology," states on page 696, that: "In a case in which even the eyes are paralyzed, it is impossible to determine clinically whether awareness is retained or lost." An EEG could show that such a patient has cerebral activity.

Apparently, the three medical experts that were asked to testify before the Bioethics Commission were unaware or unwilling to share this knowledge with the Committee. There are two other doctors: Dr. Peter Black and Nicholas Zervas, who surveyed neurosurgeons and neurologist in 1984. Only 55% of these experts required an EEG. So if that's the standard, that 55% think is proper -- just a clinical diagnosis -- then we are giving away our rights to physicians that feel this way.

Again, as I said in the Strachan case, they determined that young man was brain-dead, within 20 minutes of his entering the hospital, without an EEG.

Senator Ambrosio would like to see this horrendous court decision codified into law. Another fallacy in the excepted medical standards, was spotlighted by a report of researchers Jorgensson and Moeller, in 1981. They found that some patients who met brain death criteria could recover EEG activity after eight hours. In other words, they had an EEG, and it was flat, but eight hours later they recovered; thus showing they're not brain-dead after all.

Despite this research finding, the most widely used time interval in the United States is six hours. So if the study proved after eight hours many people come back-- The Commission that was appointed by the President recommended only six-hours, despite this scientific evidence. It was the recommendation of the President's Commission, which gave the six hour interval such wide use in determining brain death. It's not scientific, and it does put some patients in jeopardy.

There was a study; it was called the Collaborative Study of Researchers of the National Institute of Health. And the President's Commission, and other brain experts, death experts such as Black and Torres, recommend use of such fallacious and dangerous criteria, it's no consolation to me or it shouldn't be a consolation to you, that if these people are recommending criteria which are not meeting the standards of scientific studies, then this issues deserves more attention.

It's unfair, I think, for the people of New Jersey not to know in advance what the criteria are that is going to be judging them dead, and take away all of their rights. In this kind of legislation, there are no criterion. And if you pass this legislation -- if the legislator passes it, the public is not going to know what the criteria is.

The most interesting article I found about this confusion was written by our former Executive Director of the New Jersey Bioethics Commission, Alan Weisbard. He published this in JAMA -- the "Journal of American Medical Association" -- in April of 1989. In it he says, "that 55% of the physicians" -- I'd like to find the exact point -- "that one-third of surveyed physicians responsible for identifying brain-dead patients and declaring them dead, were unable to identify irreversible loss of all brain function as the criterion of death and apply it to two simple cases."

"The same was true of nearly three-fourth of another group of medical residents, anesthesiologists, and nurses who work in the areas of intensive care and transplantation." He goes on, and he coauthored this article with a Ph.D. -- another gentleman name Daniel Wikler -- and through the whole thing he says, -- and I have the point outlined, so I won't read on and on -- "The President's Commission regarding brain death, as marking not only the loss of capacity for consciousness but also the loss of the integrative function of the brain stem, after which in the Commission's view, the function of the vital organs systems fail to constitute a living organism," and here is what Weisbard said, "but in fact, these organ systems do function as a system, which is why physicians have been able to maintain brain-dead patients, slated to become organ donors."

Weisbard continues, "The whole brain concept reflects no fact about the patient's status as living or dead." Now he is the Executive Director of the Commission, and he's saying the whole brain death is very difficult to determine, and physicians and nurses and anesthesiologists, failed in their attempts to determine these criteria. And if he's admitting all of this, he comes to the conclusion in the end that rather than declaring people who are brain-dead, or under these criteria, the whole brain death as dead, instead, we should declare people who are merely comatose and have lost cognitive function, as dead.

So he's pushing it the next step which is an outrageous conclusion after finding that physicians and nurses and so on could not even come to a conclusion scientifically about the status about a particular patient as being whole brain-dead. And he knows that they can't be whole brain-dead, otherwise their functions wouldn't be working; they wouldn't have a normal blood pressure, and they wouldn't be able to change oxygen to carbon monoxide and carbon dioxide in respiration. He knows that that's a fallacy, so rather than look at the fallacy, he wanted to change the definition and say, let us declare people brain-dead who are merely -- who have lost their cognitive functions such as people in pvs or a comatose state, which is different than the whole brain death.

Based on that, I urge this Committee to not pass the brain death proposal bill that has been put before you today, because there's a lack of scientific evidence, and there's also a great deal of danger to the citizens of New Jersey.

As to the issue of the advance directives, my points are mainly that this particular legislation has many dangers. It's unnecessary, and there is a movement behind it. The purpose of the living will statute was announced in 1967, by the International Euthanasia World Conference. In 1967, they decided that in order to promote social policy of acceptance of euthanasia -- and that is by omission or commission -- a living will would be the proper way to go for it, because people would see it as a way of getting their rights.

This idea that was proposed in 1967 has been a very effective, and moving from California to New Jersey. It has been moving across the country. The people who are behind it are the Concerned for Dying, and the Society for the Right to Die, in New York. It's part of their philosophy. What you may not know is as part of their philosophy, they funded conferences at Harvard last spring. There was an announcement by 10 physicians, saying that aid and dying -- that means lethal injection, assisted suicide -- is ethical. Four to five of the physicians that made that report from Harvard -- by the way, they met in the Harvard Library, they weren't part of the University-- They were funded by the Right to Die Society in New York: Five of the physicians who made the report are board members, and the people who edited it over two or three years, are board members of the Society for the Right to Die.

This living will legislation is not an end in itself. It is a means to an end. The group -- the same 10 doctors met several years ago saying that, food and water isn't necessary for -- they call "dying patients." The same thing they are advocating now, aid and dying, for so-called terminally ill patients-- One of the doctors who's not a board member of the Euthanasia Society of New York, but was the doctor who testified in the Cruzan case -- his name is Dr. Cranford -- has written in the Euthanasia journal; the Society for the Right to Die journal -- that he sees that it is very important for people to have the right to have assisted death -- death by injection. He see this as a very important right.

Right now, there is also a group in California-- They could not get the signatures in California to get a vote on the ballot for assisted suicide. They don't call it assisted suicide. They call it aid in dying. Aid in dying was to be an amendment to their living will. Now their living will says, this living will does not condone euthanasia, by omission or commission. Then they proposed to amend their living will, which has that clause, and instead they add, aid in dying shall not be considered mercy killing -- something like that. It didn't pass in California. They took the initiative to Washington, D.C. and to Washington. In order to put it on the ballot they needed 150,000 signatures. They now have 180,000 signatures. In Washington--

ASSEMBLYWOMAN FORD: I know that the Committee finds this very interesting, but we have a very very long list of witnesses and what we're focusing on is what we are doing here in New Jersey.

MS. PERONE: Well I want to make the point.

ASSEMBLYWOMAN FORD: We could filibuster all afternoon on--

MS. PERONE: Oh, I'm not filibustering.

ASSEMBLYWOMAN FORD: --the issues that are here, but I think just in deference -- try to focus on what's there.

MS. PERONE: I'm sharing with you my knowledge, because I know that you're busy doing so many other things for the State, that you really can't focus on an issue. So I'm trying to synopsize things that I've discovered and share them with you, so that you can see the whole picture.

The only comment that I want to make is that the person and the group that is promoting this initiative in Washington -- the Hemlock Society -- a few weeks ago, the Director, Derrick Humphrey, was in New Jersey or New York on a radio program and he said-- He's certainly for assisted suicide, because he did in his first wife that way. He said, "In New Jersey, this is the only State that does not have a living will." And he is looking forward to it. Now the reason that he is looking forward to it is because the next step that is coming after it is the amendment of the living will, which is to put in aid and dying.

This is not a isolated group. He is the President of the International Euthanasia Society, or he was this summer. This is an agenda, and I want to bring it to your attention. Okay.

The dangers of this particular living will -- the advance directive -- is-- There are so many in there it's difficult to outline. First of all, the definition of "terminally ill." In our case law, in the Conroy case, a person is considered terminally ill if they will die in less than one year. When I speak to elderly people in nursing homes, I ask them, what do they think terminally ill means? And they say, that means I'm going to die in a few days. So an elderly person signing a one-page document, not knowing the case law behind definition of terminally ill, they may think it is an hour or two. By putting a one-page document in front of a person in a nursing home who may not have proper capacity in the first place-- Most patients there are either very frail, old, have lack of memory, and so on.

The second thing is, in this particular bill, they don't use the word "competent." The patient doesn't have to be competent to sign a living will, or to deny, or reject a living will. They have to have the capacity to make a health care decision. Capacity to make a health care decision is not a legal definition. It's a novel invention of the Bioethics Commission. It is not something that has any standards in the law. Competency has a standard in the law, but capacity to make a health care decision? Who's going to decide that, the attending physician, a relative, some self-appointed surrogate? The advance directive allows the appointment by selves, in certain situations, when persons are in a pvs state.

ASSEMBLYWOMAN FORD: Is it your understanding then that there is a difference between being legally competent to enter into any type of legal instrument, as opposed to what the Bioethics Commission means when it says, competent to make a health care decision?

MS. PERONE: I believe it's capacity to make a health care decision.

ASSEMBLYWOMAN FORD: That's two distinctly different capacities to make a--

MS. PERONE: Yes, there is. Competent has a long legal history. It's defined in "Black's Law Dictionary," and it has a long history in the law. There is no history behind capacity to make a health care decision. What does that mean? Does that mean the person has some kind of medical training, they know the pros and cons, and they're completely informed? It's a very new, novel, untried definition. I don't think it is proper for the citizens here.

When someone signs a regular will to give away their estate, they have to be competent. And if they're incompetent, then it can be contested. But when someone's dead, who's going to contest that they were either incompetent, or had this novel standard that they're trying to propose in this legislation?

The other thing is, I think it is unnecessary. Right now on the books we have a power of attorney law, without immunity to the person who could make decisions. I've filled out and prepared powers of attorney for my clients, either for their estate matters, or for even medical decision making, but the person who will be making the medical decisions is not immune and neither is the physician. The major danger with this legislation is giving blanket, carte blanche immunity to health caregivers -- I haven't looked at the recent change. I don't know whether it's for not using bad faith or for using good faith. Either way, I think the negative is worse.

There is no situation where any other profession has been given carte blanche immunity for their actions. As an attorney I see in "The New Jersey Law Journal" every week, attorneys being brought to task, being disbarred, because they did something unethical. There is no way that any attorney in this State would get blanket immunity for their actions. And I think in this case for a frail person in a nursing home to be required by the nursing home to stick living wills in front of them and to be educated about living wills whether they wanted to or not, the nursing home is going to be mandated to do so, for them to sign a document and not have -- be competent or incompetent, no standard there-- For them to sign something, thinking that this is good, or for them to be coerced because they think, "well this is a better thing. My children will be relieved of me, as a burden--"

These frail people need more protection than this particular living will is providing. And so, I respectfully request that this Committee read it very carefully. I do have something that I want to give you, about particular criticism I have of the legislation. The paragraphs might be off a bit because it was previously done, prior to my seeing this, but I will leave it with you.

ASSEMBLYWOMAN FORD: Thank you.

MS. PERONE: Thank you for your attention.

ASSEMBLYWOMAN FORD: Mary Strong, Citizens Committee on Biomedical Ethics?

I gave a lot of leeway, in light of the fact that Ms. Perone is a member of the Bioethics Commission and has testified before this Committee before on this issue, but I am going to have to ask that the remaining witnesses attempt to not duplicate testimony that has been presented previously. Try to summarize your points, if possible, so that we are not devoting a half an hour or so to each witness.

MARY S. STRONG: Thank you very much. Thank you, Chairman Ford and other members of the Committee, for holding this very important hearing on the bill designated as the "New Jersey Advance Directives for the Health Care Act."

I represent the Citizens Committee on Biomedical Ethics, a nonpartisan grass roots movement in New Jersey, and other states throughout the country, which provides educational forums for citizens in the general public to discuss medical ethical issues, including advance directives and the choices in health care treatment.

I am speaking not for an ideological group of people. I am speaking for the citizens who have told us certain things which we feel we must pass along.

We support the substance of Senator Gabriel Ambrosio's bill, which has passed the Senate and has been assigned to the Assembly Judiciary, Law and Public Safety Committee. This bill will provide the public with the statutory recognition of the legality of a living will. A majority of the people in New Jersey -- a large majority -- have told us they feel this is essential.

The bill specifically allows for the appointment of a surrogate decision maker. It will give health care professionals heightened confidence in abiding by the wishes expressed in an advance directive.

Our committee conducted an extensive poll, which--

UNIDENTIFIED SPEAKER FROM AUDIEMCE: Excuse me, but we can't hear you.

MS. STRONG: Oh, I'm sorry.

ASSEMBLYWOMAN FORD: These microphones do not project; they are just for recording, so you have to speak up a little bit.

MS. STRONG: Sorry, thank you. Our committee conducted an extensive poll, which was reported in July 1988. That report showed that the public supported the following points, which also corroborate the New Jersey Supreme Court's decision:

1) The primacy of the individual's right to make treatment decisions at the end of life and the belief that incompetence does not compromise the exercise of this right;

2) The endorsement of the living will as a means to secure the execution of these decisions;

3) Responsibility for making medical decisions rests with patient, family, and physician;

4) Life expectancy is not to be, in the case of the terminally ill, a primary consideration.

We urge you to approve this bill. The Supreme Court decision in the Nancy Cruzan case has aroused people's awareness of the need to express their wishes about end-of-life decisions, not only for themselves, but for the good of their families. This bill will go a long way toward fulfilling the public's desires. Meanwhile, the Citizens Committee intends to continue with its mission to educate the public about the contents of the bill.

This completes our prepared statement supporting the bill, and I now wish to make these further remarks.

The Citizens Committee wishes to make a cautionary observation if this bill becomes law: In the implementation of the law, there is no regulation nor interpretation that diminishes in any way the final authority of the patient, family, and physician to make the end-of-life decisions.

Thank you very much.

ASSEMBLYWOMAN FORD: Thank you. Len Fishman, New Jersey Association of Non-Profit Homes for the Aging.

LEONARD FISHMAN, ESQ.: Thank you, Chairwoman Ford and members of the Committee. My name is Leonard Fishman. I am General Counsel to the New Jersey Association of Non-Profit Homes for the Aging. With me is Karen Uebele, who is President of this Association.

NJANPHA represents over 125 nonprofit facilities, including nursing homes, continuing care retirement communities, congregate housing, and county nursing facilities. Our members serve more than 17,000 New Jersey senior citizens. Most of our facilities are religious, and our Board of Trustees, which is composed of 30 members who represent virtually every major religious denomination in the Stare, has unanimously endorsed Senate Bill No. 1211. Our Board is comprised of trustees who represent facilities that are Baptist, Catholic, Episcopalian, Jewish, Lutheran, Methodist, Presbyterian, and Quaker. As I have already said, our Board unanimously endorsed this bill.

Contrary to the claims of those who oppose S-1211, there is a broad and deep consensus among religious organizations and their health care facilities in support of this bill.

You have already received a copy of my written testimony. I do not intend to read it for you, in keeping with the request of Chairwoman Ford, but I want to summarize three points that I think are particularly noteworthy:

The first is a legal principle, which is that every competent adult has the right to make a voluntary and informed decision about whether to accept or to reject medical or surgical treatment. This right has been recognized by the New Jersey Supreme Court in cases from Quinlan to Jobes, and by the United States Supreme Court recently in the Cruzan case. So the question is not whether Americans have this right -- that point has already been settled -- but whether the states they reside in make it easy or difficult for them to exercise this constitutional right. Regrettably, New Jersey is one of five states in the country that does not recognize statutorily what its Supreme Court has announced judicially, which is the right that I have just mentioned.

And that brings me to the second point, which is a legal maxim that will be known perhaps to some of the lawyers on this Committee. There is an old saying that, "Justice delayed is justice denied," and I think the same thing can be said about rights. A right delayed is a right denied.

Today in New Jersey, residents of our State, and particularly senior residents of our State, are being denied their rights precisely because we do not have a living will statute in this State. The fact that we don't have such a statute has produced tremendous confusion among health care facilities, the residents they serve, families, and physicians. People who have been in charge of their lives since they became adults are deprived of the right precisely when they are most vulnerable and most need to exercise it, and the results are tragic. People who have made their intentions known in the best way they could, either orally or in writing, find that they are confronted by health care facilities and providers who feel incapable of carrying out those wishes because there is no living will statute in New Jersey.

If a right delayed is a right denied under most circumstances, it is certainly true under the circumstances where living wills are necessary, in the final days of life. If someone's request is delayed, they may never get that right because their death occurs first, and they may die under circumstances that are directly contrary to what they have requested.

Now, does this mean that decisions to withhold or withdraw life-sustaining treatment are not being made today because we don't have a living will statute? The answer is no. Those decisions are being made, and that brings me to the third point that I want to make.

This is a fact that was pointed out by the American Hospital Association in the amicus brief that it filed with the U.S. Supreme Court in the Cruzan case. In some ways, I think this is the most interesting fact that I have encountered during this entire debate. Approximately 2.2 million people die in this country every year. Well over half, about 1.3 million, die in hospitals. Of those who die in hospitals, 70% die after a decision has been made to forego life-sustaining treatment. That is just a fact of life in health care facilities today. People do not die the way they did 100 years ago. There is always some kind of medical intervention that is possible. It may be ridiculous, but it is possible. So typically patients and their families will intervene, and say, "Enough is enough. This is not what so and so would have wanted." Or, the patient makes clear his or her own intentions, as they are permitted to do by law for the reasons I have mentioned.

So, the issue is not whether such decisions will be made -- they are going to be made; they are being made every day -- but whether those involved who are making them will have the benefit of the statutory guidelines and the procedural framework that S-1211 would provide.

The real question is: Are we going to make these decisions in a way that is planned for in advance, that can be handled openly and in an orderly manner without confusion and without fear? Our facilities -- the facilities that we represent, the religious, not-for-profit facilities -- believe that their residents deserve to be empowered to make those choices on their own by planning for them in advance. It is for that reason that we urge your support of S-1211.

Now, this brings me to the final point that I will make briefly: We believe that S-1211 is an excellent bill, but we also believe that it could be made better through technical amendments that I have pointed out in my written testimony. The proposed amendments have two main thrusts: The first would be to change the function of the reviewing body, or the institutional ethics committees, which are referred to in the bill, from giving advice to providing a consultation. That may sound like a lawyerly distinction, and perhaps it is. The second is to make that process of going to a reviewing body optional instead of mandatory.

The reason we propose that the terminology be changed from "advice" to "consultation," is that there is serious doubt whether at this point in time reviewing bodies in hospitals and nursing facilities are capable of giving definitive advice about a course of treatment for an active case. This is known as prospective case review. In fact, very few institutional ethics committees today engage in prospective case review. So our thought is that at this point in time, and for the foreseeable future, it is more reasonable to expect these committees to provide a consultation, meaning an informed discussion, rather than a decision about a recommended course of action, which the word "advice" implies.

Each proposed amendment is explained in Attachment 1 of my testimony, and is noted in Attachment 2, which actually has the provisions of 1211 with the terminology written in. We have discussed these concerns with Senator Ambrosio, who has indicated to us his willingness to address them through technical amendments. I want to stress that we consider these amendments to be technical, and we believe they can be dealt with after further consultation with the sponsor.

That concludes my testimony. I would be delighted to answer any questions that members of the Committee may have. If not, I thank you very much for this opportunity to testify. Thank you.

ASSEMBLYWOMAN FORD: Thank you. Dr. Joseph Fennelly?

JOSEPH F. FENNELLY, M.D.: Good afternoon. Thank you for the privilege of being allowed to speak in favor of the declaration of death and advance directive bills. My background is that of the practice of internal medicine, with recent emphasis on gerontology. I was privileged to be involved directly in Karen Ann Quinlan's care, as well as Nancy Ellen Jobes, and I testified in the Peters case.

I started an ethics committee in a nursing home in 1970, as well as an acute care hospital in 1986. I am Vice Chairman of the New Jersey State Medical Society Bioethics Committee; Vice Chairman of the Citizens' Committee; and a founding member of the Bioethics Commission.

My basic concern is how the absence of clear laws on both living wills and brain deaths adds to the loss of trust between doctors and patients. The plight of Karen Ann Quinlan exposed the problems of unrestrained technology as it further distanced the breakdown of the doctor/patient relationship. As spokesperson for the Morris County Medical Society of 1975, I stated that the absence of a community of caring and concerned individuals immediately available to assist patients, families, and physicians in teasing out the issues involved in these tragic choices, namely ethics committees, forced the fact that the courts had to be the only form available to examine these issues.

Parenthetically, in 1975, at a house call on Thanksgiving Day, I was asked by one of the 15 members of this

Thanksgiving dinner how I felt about Karen. I turned and queried each member of this church-going group, and each and every member, from the single lady of 70 to the assistant to a Santa, said, "I would not want to live like Karen Ann Quinlan," which is not new material.

Since 1976, I have seen increasing changes in medicine that reduce communication, dialogue, and trust. There is a reduced number of primary care physicians, many more specialists, and less people interested in pursuing medicine as a calling. These changes are, in part, fueled by a concern regarding malpractice and the larger issue of civil and criminal liability. As an aside, my son graduated medical school in Newark in 1988. Of the 20 people in this group just having had a course in trauma, when they were asked if they would stop at an accident, he was the only one who said, "Yes, I would." So, these are real problems.

One of the problems in speaking and lecturing to seasoned physicians, to residents in training, and to medical students, is that they all reject the living will for one simple reason: "If it ain't legal, I don't want to hear it." Also, the patients and the families have the same feeling. They know it is good, but they say, "Is it legal?" It is an intuitive, reflex thing, despite the fact that following Cruzan, the Citizens Committee and the Commission had over 10,000 requests for living wills in a matter of weeks. So there is a desire, but it tends to fall.

I would like to also share, in closing, my thoughts about being a member of the Bioethics Commission. You have this material, but I would like to say that from its inception five years ago, I have learned what all of you understand: the necessity in a pluralistic democracy for compromise. It is very, very painful to be told, as a physician, that we must submit our sacred relationship to some kind of external oversight. It is very difficult to reconcile a patient's heartfelt wishes about brain death with the medical and life realities of the futility of total brain death. However, the need for respecting religious beliefs, in my opinion, is very, very important.

Having been present at all but one of the hearings and meetings held throughout the State, it is my opinion that these bills before you related to brain death and advance directives represent the necessity to reconcile the wishes of the patients and families, the needs of the medical profession, and the compelling State interests, which conflict with the equally important values and beliefs of individuals and religious groups.

In summary, the majority of the public desires advance directives, and passing these bills will go a long way toward reducing the distrust between doctors and patients, and will increase the capacity for shared decision making in the best interest of the patient and the public.

I want to publicly thank the State of New Jersey, the Governor, the Senate, and the Assembly for having the vision to create a Commission which has stretched the notion of professionalism, and I hope to serve on it in the years to come.

Thank you very much.

ASSEMBLYWOMAN FORD: Thank you, Dr. Fennelly. Valerie Brown, New Jersey State Bar Association.

VALERIE BROWN, ESQ.: Good afternoon, Madam Chairman. My name is Valerie Brown. I represent the New Jersey Bar Association. With me this afternoon is Mr. William Isele. He is the Chair of the Bar Association's Health and Hospital Law Section, and a former counsel to the American Medical Association.

First of all, let me thank you and commend you on your leadership on this issue, and also thank and commend Senator Ambrosio on his strong support of this legislation.

The Bar Association is here to testify in support of both the living wills bill and the Declaration of Death Act, with amendments. Mr. Isele is here to discuss some of the legal aspects of both of those initiatives. I would like him to just take a few moments of the Committee's time to address those issues.

WILLIAM ISELE, ESQ.: Thank you, Valerie. Thank you, ladies and gentlemen, for hearing us this morning -- this afternoon, excuse me. Considering the lateness of the hour, I will make a promise that no one believes when lawyers say it: I will be brief.

As Valerie has already stated, we support S-1208, the Declaration of Death Act, but without the religious objection -- without the religious exemption, excuse me. You have heard that the Supreme Court of the State of New Jersey has recognized neurological criteria for the determination of death. This morning you heard Paul Armstrong say that 49 states have adopted the Uniform Definition of Death Act, or a similar statute. This began with the adoption in Kansas 20 years ago, in the year 1970, of the first determination of death act in the United States. It has been 20 years, and now all of the other states except New Jersey have some form of a determination of death act in their legislation.

We strongly support the adoption of a similar provision in the New Jersey statutes. However, we believe that the religious exemption is unworkable. It places an enormous burden on physicians to determine the religious beliefs of patients who at the time the determination is being made, cannot speak for themselves. This is the key -- speak for themselves.

We certainly do not object-- Len Fishman just told you very eloquently that the law -- a long-standing provision in the law -- is that the competent adult patient has the right to determine whether or not medical care should be given to them. We strongly support that. However, if the physician is to go behind the patient, go around the patient, and communicate with other people besides the patient, what we end up dealing with is nothing more than speculation; what others think the patient's religious or personal position may be. It is very difficult to legislate speculation.

Please understand, we have no disrespect, no insensitivity for those religious groups which reject the concept of neurological death. We certainly believe that they have the right to their opinions, just as others have the right to express their opinions. We believe that the statute without the religious exemption, which has been in effect in 49 other states for many years, can work here in New Jersey.

With regard to the second bill -- Senate Bill No. 1211 -- the Bar Association also supports this bill, and we have shared with Senator Ambrosio amendments which, if included, will make this bill less burdensome and more available to the public.

Again, as has been stated before, the purpose of these bills is to encourage and facilitate the average person's ability to state his or her wishes and be assured that those wishes will be followed. The amendments that we recommend -- and we have shared copies of them with the Committee -- will permit this in a much broader way.

First of all, we desire an amendment which would make consultation -- Len has already discussed the importance of consultation, rather than advice, so I won't repeat that -- but to make consultation with institutional and regional review bodies voluntary, and not mandatory. We do not believe that the institutional and regional review bodies as contemplated by the Governor's Commission, or by Senator Ambrosio in his drafting of this legislation, were ever intended to be death tribunals in the form of mandatory reviewing bodies the physicians must submit to in order to have decisions made as to whether a person should live or die. Making such advisory panels voluntary removes our concerns in this regard.

Secondly, we urge the Committee to consider amendments which would include nutrition and hydration with other forms of medical treatment upon the explicit instruction of the person signing the living will. We agree with our Supreme Court that there is no legal distinction between artificial nutrition and hydration and other forms of medical treatment.

And finally again, to broaden the statute, rather than to narrow it, the statute, as currently drafted, requires witnessing of the document by two adult witnesses. We would submit a technical amendment which would also permit acknowledgement before a notary, the purpose of that being to encourage people to make treatment directives. Some may find it more convenient to sign one of these directives before a notary than to go out and get two witnesses to witness their signature.

In conclusion, Senator Ambrosio told you that 45 states have adopted legislation permitting living wills. This bill is one of the most comprehensive in the country. It is a bill which should be clear and comprehensible on its face, without having to look elsewhere. We hope the amendments that we suggest will make it more so.

Thank you for your attention.

MS. BROWN: Thank you.

ASSEMBLYWOMAN FORD: Thank you. I think what we are going to do is take a little bit of a break -- about a 20-minute break -- in case anyone has to make phone calls, or whatever. Then we will reconvene about-- Let's make it about 1:45, okay?

(RECESS)

AFTER RECESS:

ASSEMBLYWOMAN FORD: We are ready to start again. Thank you for allowing us to have that time to break. Are we ready to go here? (affirmative response)

Steven Friedman?

STEVEN FRIEDMAN, ESQ.: Thank you very much. I will try to be very brief.

ASSEMBLYWOMAN FORD: That would be greatly appreciated, I am sure, by everyone present.

MR. FRIEDMAN: I am an attorney practicing locally with a law firm, and my practice is restricted to the areas of estate planning. I probably see, in my practice, 500 to 600 or 700 people per year as clients. I give seminars to civic organizations and religious organizations comprised mostly of senior citizens. I probably speak to another 4000 to 5000 people per year. People care about what happens to their assets at their death and people care about nursing homes and things like that. But there is one thing that constantly comes up as absolutely number one in the minds of everyone I have ever spoken to who is over the age of about 65, and that is the living will. The failure of the State of New Jersey -- of the Legislature -- to date to pass a living will bill, if you will, has just been a source of frustration, not only for myself as a practitioner, but even more so for the clients to whom I cannot give a definitive answer or an assurance that their medical desires--

They go very deep. They are not real superficial, like, "Oh, yeah, I don't want to be kept alive by artificial means," but very deep, strong feelings that they would not want to be kept alive by artificial means, or have nutrition or hydration forced upon them.

I would encourage the Committee and the Legislature to heed the people of the State of New Jersey who are crying out for this. For people in their 30s and 40s to not deal with it, who say, "It is not that important," or, "A living will statute is not mandatory--" I think that ignores the fact that we have a very large senior citizen population. It is growing, and those are the people who really should be heeded.

On behalf of those people, and the people I have spoken to in my career, I would encourage the passage of Assembly Bill No. 16, or Senate Bill No. 1211, in its present form.

With regard to the actual contents of the bill itself, it appears to provide for everything. A lot of the states that have passed living will statutes have had the effect of not expanding the right to die, if you will, or the right to make a medical decision, but have had the effect of restricting it by providing specified language, which this bill does not. To provide for a particular format to be used, and to refuse to accept anything varying from that, I think just becomes restrictive, and would put us in a position where we would be worse off than under present law.

There has to be some assurance, some absolute specificity in the bill, and I believe that the bill under consideration today -- Assembly Bill No. 16, or Senate Bill No. 1211 -- would meet that requirement.

Thank you.

ASSEMBLYWOMAN FORD: Thank you. Rob Holmes, from the New Jersey Hospital Association, had to leave. He just wanted me to state for the record that the Hospital Association agrees with the viewpoints expressed by the New Jersey State Bar Association on these two issues.

Ritamarie Rondum?

RITAMARIE G. RONDUM: Good afternoon.

ASSEMBLYWOMAN FORD: Good afternoon.

MS. RONDUM: Madam Chairman, Assemblyman Naples: The New Jersey State Legislative Committee of the American

Association of Retired Persons selected advance directives for health care as a major priority in its legislative program for 1989 and 1990, and has previously testified in support of such legislation.

Nationally, the American Association of Retired Persons supports legislation permitting competent adults to execute advance directives which explicitly state their medical treatment choices or to designate someone to make these decisions for them in the event they should lose their decision-making capacity. The AARP, as a national policy, maintains that medical treatment choices should include the withholding or withdrawal of artificially provided nutrition and hydration.

In addition, the New Jersey State Legislative Committee of AARP has twice prepared comments on the rules of the Office of the Ombudsman for the Institutionalized Elderly objecting to the omission of consideration of advance directives in the performance of its advocacy and investigatory functions, and on its failure to place upon itself reasonable time constraints in the completion of investigations of "abuse" when patients have executed advance directives for their own health care.

It is now time for us to put aside fantasies and fairy tales that when our time comes, we will be in our own beds surrounded by a loving and grieving family, or that the fairy prince will come to Sleeping Beauty in her coffin and with a kiss awaken her to live happily ever after. It is time for realism. It is time for the State to do the single thing that the State does better than anything else: protect our freedoms.

The legislation you are considering does not require any one of us to write out instructions for our health care, or to choose a person to make those decisions for us. With this bill as law, we can choose to do nothing at all. We can walk out of here and gamble that we will go home safely. Or, we can take the future into our own hands, face the possibility of our own incompetence, freely state our wishes for our health care, and expect that our wishes will be respected. That is our right. We ask no more than that the State guarantee that right and respect the choices we made when we were able.

We find that Assembly Bill No. 16 and Senate Bill No. 1211 address the concerns of the AARP in New Jersey. These bills are comprehensive; they are circumspect; and they are compassionate.

They are comprehensive because of the multitude of voices which are heard. Members of the Bioethics Commission did not give birth to model legislation for advance directives for health care without pain. These bills will not make their way through this Committee nor through the Assembly without pain. But they do show that it is possible to achieve a better balance than we now have between the interests of the State in the preservation of life and the interests of the patient in the control of medical treatment. The comprehensiveness of these bills alone requires your respectful attention.

These bills are circumspect because they succeed in protecting my individual rights, while simultaneously protecting the rights of others -- those about me concerned with my health care. These bills acknowledge that each of us has created our own unique code of behavior, our own set of ethical standards and moral codes, and these bills allow each of us to act with dignity within that framework.

And these bills are compassionate because they allow for the mischievousness in our nature. These bills recognize what physicians call the "vacillating patient." These bills are so compassionate that they recognize that even within my own incompetency, within my own disturbed reality, I may sense abuse and disavow my own advance directive.

Who among you can discover a reason to abstain or to deny passage of these bills?

Does anyone have any questions? (no response)

ASSEMBLYWOMAN FORD: Thank you very much for your testimony.

ASSEMBLYMAN NAPLES: Thank you.

ASSEMBLYWOMAN FORD: Mark Zucker -- Dr. Mark Zucker?

MARK ZUCKER, M.D.: Good afternoon, Madam Chairman -- Chairwoman, I guess. My name is Mark Zucker, as you just announced. I am the Director of the Heart Transplantation Program at the Newark Beth Israel Medical Center.

I would like to just tell you a couple of things, and be fairly brief if I can. But what I am going to do, rather than present opinions, I think, is present you with some facts as to why I, and probably other members of the transplant community object to Senate Bill No. 1208, in particular paragraph 6a.

Newark Beth Israel, for your information, at the pressent time, is the only hospital in the State of New Jersey performing heart transplantation. This was permitted by the Department of Health and the Commissioner of Health under a Certificate of Need for a two-year demonstration project. I personally came to New Jersey from Chicago in 1989, having been a member of the Heart Transplant Program at Loyola University, which was a fairly busy heart transplant program in the midwest, and I was joined by Dr. Suzesi, who joined us at Newark Beth Israel in January 1990. He came to New Jersey from Columbia Presbyterian in New York, which, at the present time, has the busiest heart transplant program in the nation. I think that together with Laszlo Suzesi we have kind of put together a fairly effective and a fairly talented team of surgeons and physicians.

Initially, the development of the program was a little bit slow, primarily because I think we were competing with New York and Philadelphia. But ultimately we began to have a steady stream of patients, and within about two or three months we started to see two or three patients a week, to the point where between January of this year and November of this year we saw 70 patients in evaluation for heart transplantation. Ultimately we accepted 20 to 25 of these patients for transplant, but between January 1, 1990 and November 1, 1990, we actually transplanted only seven patients.

For comparison by you, Columbia Presbyterian, during that same period of time, 17 miles away from us, in a different state, though, transplanted 100 patients, and Loyola University in Chicago, during that same period of time, transplanted 35 or 40 patients. I do not know the exact number.

Now, I would be the first to admit that both of these centers are established centers that have been here for some time, but the activity level at the two centers is not necessarily a reflection of a larger pool of recipients, but much more a reflection of a larger pool of donors. Unfortunately, the situation in New Jersey is not improving by any means. The United Network for Organ Sharing, which is the national registry and the national data base, reported that in 1988 there were 89 organ donors in this State, but in 1989 there were 80 organ donors, representing a 10% decline in one year.

Those numbers, in and of themselves, do not really give you a good insight as to the picture, so let me compare that to other states in the nation. New Jersey ranks 46th in the nation right now in terms of organ donations. The only four states that are worse than we are right now are: Mississippi, South Carolina, South Dakota, and Rhode Island. South Dakota and Rhode Island do not even have transplant centers, which may explain the low organ donation rate in those states. If you look only at the states in which there are transplant centers, there are 41 states, and New Jersey ranks 39th.

The Commissioner of Health is trying to encourage the development of a tertiary care referral center in this State. She is doing that by setting up liver transplant programs, kidney transplant programs, heart transplant programs, and perhaps in the future, a lung transplant program. Interestingly, at the same time that the State of New Jersey is attempting to encourage the development of tertiary care transplant facilities, the Federal government is turning around and trying to restrict the development of those centers to busy, active centers.

So what they have done -- the Federal government, that is -- is say: "Medicare will only pay for transplants at centers that have performed -- for example, in terms of heart transplantation -- 35 heart transplants, maintaining a minimum heart transplant rate of 12 per year, with a 73% survival."

About two or three weeks ago, I received a notice from Blue Cross/Blue Shield asking us to provide them with our statistics and our data. I suspect that was the beginning of their attempt to follow the Medicare guidelines, and also adopt similar provisions. What will happen ultimately in the next year or two, I believe, is that Metropolitan and all of the other third-party carriers will require that we meet the same criteria that Medicare requires.

The practical implication of that is, only the wealthy or the uninsured or unemployed in the State will be transplanted, because anybody who is insured will be sent to centers that their insurance carrier has made deals with or negotiated fixed prices with.

The reason I spent the last few minutes providing you with this information is, I think you need it in order to understand my objection, and the objections of the others to any bill such as Senate Bill No. 1208, which, as presently proposed, would impact negatively on organ donation in the State of New Jersey. Anything at this time that impacts negatively on organ donation has to be viewed with the strictest of scrutiny. By that, I mean, to be more specific, that the legislation has to-- When we evaluate that legislation, we must look to see what the impact of that legislation is on the potential organ donor, and weigh it against the impact of the legislation on the potential organ recipient, and balance the interests of those competing parties.

The legislation itself must be internally consistent. And, most importantly -- not most importantly of all -- the legislation must not impose any undue or unreasonable or unrealistic burdens on those who are responsible for exercising its provisions.

If you view Senate Bill No. 1208 with the strictest of scrutiny, what will happen is, it is going to worsen an already critical donor shortage. It will have a far greater adverse impact on the lives of potential organ recipients than it will on the families of potential donors. And, as I said before, it has to be internally consistent. Senate Bill No. 1208 is not internally consistent. It is intended to try to help physicians to declare patients brain dead, and ultimately encourage organ donation. But any bill that requires physician conduct-- Or, let me change that: Any bill that requires that the physician conduct an extensive investigation to determine if a declaration of death, at least on -- let me see if I can quote this for you -- "neurological criteria, would violate the personal beliefs or moral convictions of the patients."

My point is: This paragraph will not encourage organ donation at all. In fact, it will discourage it, and it will limit the application of neurological criteria in the determination of death in New Jersey.

Now, assuming for practical purposes that it is easy enough to speak to a family member or a friend or a religious person -- okay? -- it does not necessarily follow that those individuals possess an accurate -- possess accurate information regarding the beliefs of the patient. Most patients have not discussed with their families or their friends or their clergymen what they feel about brain death or organ donation. In those instances, in fact, when we have conflicting data, where one person says, "Yes," and one person says, "No," what am I, as a physician, supposed to do? Am I supposed to believe the wife, the children, the husband, the clergy, the friend? It makes it very difficult for us to decide.

In practice what will happen is, physicians will say: "This is not worth it. It is not worth it to me to go out and try to investigate and conduct these extensive queries of family members, when they won't do it at all."

Let me ask a last question, rhetorically, I suppose, but let me say: Why should I assign such a high degree of credibility to the words of a family member or a friend, unless it is there in black and white, in writing? How am I supposed to know exactly what that person himself really believed? You have to be able to know the personal belief of the patient, not the personal belief of the surrogate with whom you are speaking.

And finally my last point would be: The legislation is really an attempt to regulate the declaration of brain death. I am not sure how much that legislation is needed in its present form, or should I say, as presently proposed. Brain death is being declared across this country everyday. Ninety-five percent or more of the time it is done quite effectively between the physicians, the families, the clergy, the nurses, and the hospital administration, without requiring legal intervention, hospital attorneys, or the courts.

The bottom line to all of this is: As I see Senate Bill No. 1208, it is going to impose an unrealistic burden on the well-intentioned physicians, social workers, nurses, and bereavement counselors. That may benefit the minority, but it will do so at the expense of the majority.

For these reasons, I would ask that you reconsider Senate Bill No. 1208 in its present form, and if you do adopt it, adopt it by amending it and excluding paragraph 6a.

Thank you.

ASSEMBLYWOMAN FORD: Thank you, Doctor.

ASSEMBLYMAN NAPLES: May I have a copy of your statement? You can mail it to me. I am in the book -- Assemblyman Naples. Okay?

DR. ZUCKER: Yes, definitely.

ASSEMBLYWOMAN FORD: Rita Martin, Citizens Concerned for Life.

RITA MARTIN: Good afternoon. My name is Rita Martin. I am the Legislative Director for Citizens Concerned for Life of New Jersey. Citizens Concerned for Life is a statewide organization committed to the principle of the value of life and also acting upon that to protect vulnerable life, no matter its age or condition. I want to thank this Committee for giving me the opportunity to be heard.

The Committee has before it today a panoply of bills dealing with issues at the end of life. As others have said, many of them are very similar. I will address my comments principally to S-1211, the Advance Directives for Health Care Act, which seems to cover, more intently, the issues involved, and make a few comments on A-2467 because it addresses an additional aspect of the debate.

Citizens Concerned for Life recognizes the right of individuals to make decisions regarding their own health care, and to make plans for that care when they, themselves, are no longer able to do so. And we recognize the time and effort expended by the New Jersey Bioethics Commission in preparing this proposal. I will, as an aside, tell you that I am a member of the New Jersey Bioethics Commission. Nevertheless, we feel that the bill, as written, raises some vexing moral problems and lacks sufficient safeguards for some of our citizens.

Our principal concern is the provision allowing the removal of treatment and fluids and nutrition from nonterminally ill patients.

Senate Bill No. 1211 creates a class of patients termed "permanently unconscious," and includes in that class those patients in irreversible coma and persistent vegetative state. Both of these conditions are difficult to diagnose with certainty. These patients, for the most part, are not terminally ill, do not have any underlying pathology that will kill them, but are vulnerable simply because they are disabled. The bill creates a discrimination against a class of patients because they are in a state of dependency, denying them safeguards available to other patients and making them candidates for death by starvation.

The bill adds that the definition of "permanently unconscious" is "without limitation," meaning other categories can be added. The circle of similarly vulnerable patients is very wide. Would those with Alzheimer's disease be added? Would AIDS patients be added? Would those with mental retardation be added? Anyone who doesn't interact as people would like them to could become vulnerable to decisions to withhold basic care -- we are not talking about extraordinary or unusual care, we are talking about basic care -- solely because of permanent disability.

The bill also allows competent patients with a serious, eventually terminal disease to opt for non-treatment and to refuse fluids and nutrition if they perceive the burdens of their illness to be too overwhelming. This seems to be a step toward legalizing suicide and assisted suicide. Patients in these circumstances should be offered information, counseling, and support to help ease their burden, rather than offering them the right to cause their own deaths. The State does have a vested interest in preserving life, even impaired life. Certainly, the intent was not what I have said, but when you look ahead to the way the wording is and what could possibly be done -- and we have seen before how wording is changed -- people kind of challenge what it means.

I would like to respond to Senator Ambrosio's statements earlier this morning -- his remarks regarding the inclusion of an explicit instruction in the bill regarding nutrition and hydration. It was included as a compromise, but it was included because it was recognized that most people would not understand that nutrition and hydration might be included as medical treatment to be withheld. So a specific statement would be needed to say that that was their understanding, and that is why it was done that way.

Treatment withdrawal decisions should become applicable only when the patient is terminally ill, not before. Moreover, decisions to withhold or withdraw artificially provided fluids and nutrition should not be permitted if doing so would, in itself, cause death, rather than death being caused by the underlying illness or injury.

S-1211 does not include an exception in cases of pregnancy. An advanced directive should not--

ASSEMBLYMAN NAPLES: Could you repeat that, please, that last sentence? I lost my place for a second.

MS. MARTIN: S-1211 does not include an exception in cases of pregnancy. An advanced directive should not be effective during the course of a pregnancy. A woman who has chosen to continue her pregnancy, and is now in a critical medical condition would certainly want her baby protected if at all possible. A number of other states have included such clauses in similar legislation. We would like to see inserted a statement similar to Florida's Life-Prolonging Procedures Act, which states an advanced directive shall have, "no effect during the course of a pregnancy." We contend that most younger people who write "living wills," or advanced directives, assume they will become operative in the future when they are old. They do not consider what might happen should a critical condition arise tomorrow. Therefore, should the unexpected happen, we contend a pregnant mother would more than likely opt for treatment if it would save her baby's life.

S-1211 limits the right of institutions to refuse to participate in treatment removal decisions to only religiously affiliated institutions. This places an unfair burden on institutions and on staff of privately run corporations which have strong moral convictions against treatment withdrawal. Transferring a patient to another institution is not always the answer, because the staff is still cooperating in the decision if this is done. And, what if the patient refuses transfer? The right to refuse to participate in treatment withdrawal decisions should be extended to all institutions where staff and institutional policies conscientiously object to such participation. A requirement could be added that this policy be in writing and made known to patients before entering the institution. If this limitation is allowed to remain in the bill, we may see the closing of some of our sorely needed nursing homes.

All life is precious. People should not be abandoned because they are dependent and disabled. Best efforts should be made to recognize the uniqueness of each patient, to keep them comfortable, to help them live with dignity until death takes them. We recognize the heartache and suffering of the families of patients with severe and long-term illnesses, but the pain of the family does not justify taking the life of the patient, nor should we allow the patient to take his own life.

We request that this bill not be released from committee in its present form.

I would like to maybe clarify Assemblyman Shusted's question earlier, when he was asking about those who support or do not support the bill. In the report itself from the Bioethics Commission, notice that it was unanimous for the brain death bill, but for S-1211 -- for the advance directive -- 17 commissioners voted for it. There were six dissenting opinions and one statement of concern.

ASSEMBLYWOMAN FORD: Well, you weren't voting-- Were you voting specifically on draft legislation?

MS. MARTIN: When we took the vote on the bill itself, the final draft of the bill, that was the vote.

ASSEMBLYWOMAN FORD: Okay. So, on the one it was unanimous, and on the other one--

MS. MARTIN: There were 17 for; six dissented, and put in minority or dissenting opinions; and then one statement of concern from one of the commissioners who did vote for the bill was also put in.

Just a few comments about A-2467, which attempts to address situations where patients have not left written instructions: We feel the whole bill is hampered by the definition of "terminally ill." The bill says that terminally ill means having an incurable condition which will ultimately cause death and the application of life-sustaining treatment serves only to postpone the moment of death.

We submit this definition is far too vague because it can cover anyone from the patient on dialysis to the diabetic who must take insulin every day to survive. We also submit that the whole issue that A-2467 addresses is extremely complicated, even more so than the issue we have before us, and needs a great deal more study before legislation is attempted.

ASSEMBLYWOMAN FORD: I don't think that will be-- You know, what I tried to do in developing this agenda was put everyone's bill up for discussion purposes.

MS. MARTIN: Okay.

ASSEMBLYWOMAN FORD: I don't think that is probably going to be--

MS. MARTIN: Well, okay, the point is in my statement.

ASSEMBLYWOMAN FORD: I appreciate your input on that.

MS. MARTIN: Except for S-1208 and its companion, A-1413, which deals with neurological determination of death, we feel all the bills under consideration here are flawed and should not be released from committee.

I have included with my testimony a position paper on S-1208, which we do support. We do not oppose S-1208. We -- going along with some of the other concerns that were voiced here -- realize that we must monitor very closely the Board of Medical Examiners as they set the protocols that go with S-1208.

Thank you very much.

ASSEMBLYWOMAN FORD: Abbott Kreiger?

ABBOTT KREIGER, M.D.: Good afternoon, ladies and gentlemen. I am here as a physician and neurosurgeon to discuss the Declaration of Death Act. I would like to say -- and this is apropos to my colleague from Beth Israel Hospital in Newark -- as surgeons are able to transplant human hearts with greater facility, and implant an artificial heart to maintain circulation, the brain-directed concept of death has replaced the heart-directed concept.

The basic requirement for the declaration of brain death in the United States is irreversible loss of both caudacal and brain stem activity. Practically, this requirement has three components: absent brain stem reflexes; absent caudacal activity; and the demonstration that this state is irreversible. Medical consultants of the President's Commission of Ethics and Biomedical and Behavioral Research have proposed guidelines for the declaration of brain death which consolidate the experience and attitudes in the United States thus far.

These should be considered definitive today for the diagnosis. They begin by affirming that death of the brain is to be considered a valid criteria for declaring brain death. Brain death is then defined as an irreversible cessation of all functions of the entire brain, including the brain stem. It is established by showing that caudacal and brain stem functions are absent and reversible causes are excluded.

In general, statutes, or court decisions do not specify the specific guidelines to be used in declaring death by brain criteria. They confirm that brain death will be taken as synonymous with death. An example is the model statute of the National Conference of Commissioners of the Uniform State Laws, which states: "For medical and legal purposes, an individual who has sustained cessation of all functioning of the brain, including the brain stem, is dead. The determination of death under this section must be made in accordance with reasonable medical standards. The medical profession is expected to develop its own guidelines."

With the pronouncement of death by traditional cardiopulmonary criteria, pronouncement of death by neurological criteria, there is no need for patient's family consent. Certainly, the family should be fully informed concerning the processes and meaning of the brain dead protocol. However, to request family consent for the death certification or life support withdrawal, is to suggest to them that they, and not the doctors, are to make the final decision whether to prolong life or allow death.

Such a suggestion is false and misleading, as the patient already has been determined to be dead. The close relative asked to acquiesce or consent to life support withdrawal is then forced into an emotional and ethical dilemma. A final consent to withdrawal is often followed by a deep sense of guilt that he or she has contributed, in some manner, to the death of a loved one. The determination of death is, and always has been, a medical decision.

When the first concept of brain death arose, which was that brought forth by the Harvard Ad Hoc Committee in 1968, they felt, at that time, and I quote: "It is unsound and undesirable to force the family to make the decision." I endorse that position. I feel that if that portion of the bill is incorporated into the Act, it is going to make it very confusing; it is going to be very disruptive; and the number of donors available will be significantly decreased.

In addition, on another note, New Jersey has been in the forefront in dealing with ethical issues in this area, beginning with the Karen Ann Quinlan decision, followed with the Conroy decision. And none of the other states which have brain death laws include anything other than the physician making the decision of being brain dead.

Thank you very much.

ASSEMBLYWOMAN FORD: Thank you, Doctor.

Is Mr. Traynor here? I didn't have him marked down. Richard Traynor? (no response) Lloyd Zucker -- Dr. Zucker?

LLOYD ZUCKER, M.D.: I, too, am here as a neurosurgeon and physician, working in a different setting than Dr. Kreiger, in a community setting in community hospitals and in New Brunswick at the Trauma Center there. I will try to limit my comments, as many of them would be repititious after what Dr. Kreiger has just said.

One thing that has been paraded, unfortunately, in front of the Committee seems to be an air that much of what we do is fraught with a lot of indefiniteness. I would like to think that in the past decade that we have been involved with the maturation of a definition of brain death, the ability to make that diagnosis and the early errors that were made in that diagnosis have been corrected.

We have heard a lot of things on confirmatory tests, and whether or not they should be included. Specifically things that have been mentioned are things along the line of the EEG and some of the insecurities about that. I think those comments, without an appreciation of where the EEG is being performed, lead to inaccuracies and inadequacies. The EEG is a very hard test to perform adequately unless it is in a well-controlled setting; in a room that is isolated from outside electrical interference. Let it be said that in the intensive care unit where there is a patient that one is trying to declare brain dead, with monitors, hypothermia blankets, and a host of other machines, the ability to interpret EEGs is often left open to question.

The exclusions that have been accepted in many of the national criteria are things that we apply to the letter of the law as far as we can see it. The problem we have a lot of times, or the problem that I think is surfacing here, is that we are establishing a diagnosis of brain death and we are not defining brain death. We are just putting that forward and saying people can be diagnosed as brain dead, without establishing the criteria by which we are going to do that.

The issue that Dr. Kreiger put forth on including the family of the patient, I think, is of the utmost importance. In a situation where one is finally sitting with the family and a diagnosis of brain death has been tendered, I think they are looking to the physician -- and the clergy is often involved at that time -- for a definitive statement. They are not looking for the insecurity that is added into this by asking whether or not one believes in brain death, or have there been moral or religious expressions against brain death. I have not come across -- in a decade -- a situation where a family has ever voiced that situation. Additionally, I don't think that any of us who have been involved in a situation have ever used the diagnosis of brain death as a way to bludgeon a family into submission. It is a clinical, medical, scientific diagnosis, and not a religious or ethical question we are putting forth to them.

The other question is, or I should say the other statement, I think, is, to my knowledge no patient who has been diagnosed as brain dead utilizing -- in large quotes -- the "nationally recognized criteria with the confirmatory tests--"

I have not been able to find evidence that any of them have ever shown useful return, or return of function. They have all progressed to a cardiopulmonary standstill from that point in time. Therefore, brain death is as valid a yardstick of death as cardiopulmonary death. In an emotional sense, if one were to say that the religious, the moral, and the ethical issues reside in the telencephalon -- in the thinking brain -- when the brain is dead, then those issues are put to rest.

Thank you.

ASSEMBLYWOMAN FORD: Thank you.

JOHN TOMICKI: (speaking from audience) Excuse me, Madam Chairman. Did you call Mr. Traynor's name? I just have a brief statement to make, if I may.

ASSEMBLYWOMAN FORD: Sure. I was going to ask you to come forward, also. I didn't have Mr. Traynor on my list, and I didn't know whether or not he had shown up, or if we had just missed him.

MR. TOMICKI: Okay. For the record, my name is John Tomicki. I am the Associate Legislative Director of the New Jersey Right to Life Committee. In deference to time-- Mr. Traynor, who is our immediate past President of New Jersey Right to Life, has prepared testimony -- he could not be here today -- on the living will bill, so we want to keep our record straight that we are in opposition to the living will bills. And, with the Chairman's acquiescence, I would like to offer his testimony in its written form to be inserted in the record at this time -- as if given at this time.

Just to generally summarize, Mr. Traynor's testimony goes into more than the general aspects of--

ASSEMBLYWOMAN FORD: It will be included in the transcript as if it were given in, you know, its entirety.

MR. TOMICKI: If that could be done, I would appreciate it.

I would like to just generally say, this is not really an informed consent bill. It is an uninformed consent bill, because literally, as has been said, nobody would sign a mortgage with a bank -- okay? -- if they didn't know what all the details were. So, with floating standards, with people being able to change their minds at sometime in the future, with medical technology being changed, they are being asked to sign something now to state in the future. It probably is not even necessary, in light of the fact that we do have a power of attorney, but there is a whole generalized aspect to the opposition we of the New Jersey Right to Life have to the living wills. Mr. Traynor goes into this very adequately in his presentation.

I appreciate the Committee's responding to my request to insert it at this time as given, because we from the Right to Life Committee have a more detailed presentation to go into later on.

ASSEMBLYMAN NAPLES: John, do you have copies of the statement?

MR. TOMICKI: I can make them. They are, like, his notes, with a few changes on them.

ASSEMBLYMAN NAPLES: All right, but you are going to get them to us.

MR. TOMICKI: We will send them to all members of the Committee.

ASSEMBLYWOMAN FORD: Would you like to stay here and just give your testimony anyway?

MR. TOMICKI: Well, there are the three of us, and we have a lot of detail to go into on the bill. It is up to the Chairwoman, if you would like us to.

ASSEMBLYWOMAN FORD: Well, you know, I would like you to be able to have your say.

MR. TOMICKI: Pardon?

ASSEMBLYWOMAN FORD: I would like you to be able to have your say now.

MR. TOMICKI: Oh, I am going to stay, but do you want us to go now? I can bring up the rest of our Committee.

ASSEMBLYWOMAN FORD: Yes, yes.

MR. TOMICKI: In noting for the record that, unfortunately, Assemblyman Shusted and Assemblyman Stuhltrager are no longer with us, I will definitely send copies of that to all of you separately, as well as communicate directly with the Committee, so that you can insert it into the record at that time.

ASSEMBLYWOMAN FORD: The only request I would have-- As I said previously, I know you have extensive testimony prepared, but I would ask that if there are matters that are repetitious, you know--

MR. TOMICKI: That is exactly why we did that in this area.

ASSEMBLYWOMAN FORD: All right, thank you.

MARIE NIEMEYER: My name is Marie Niemeyer. I am Legislative Director for the New Jersey Right to Life Committee. I would like to thank Assemblywoman Ford for the opportunity to be here today, and also the other members of the Committee.

Patricia Coyle is our Medical Research Director. She will present the testimony that we have prepared together. It will cover various aspects of the Declaration of Death Bill. We are in opposition to Senate Bill No. 1208 and Assembly Bill No. 1413. Some of the areas that we will cover in the testimony will be patients who meet the neurological criteria-- Are they dead or are they alive? We have scientific testimony showing that they are alive and that the criteria has since-- The Harvard criteria is unscientific.

We will give this evidence, and will also go into some of the philosophical and religious aspects concerning brain death. Then John will end up with a summary.

MR. TOMICKI: With specific recommendations for changes, by the way, which I didn't think would be possible, but as it turns out, it is.

PATRICIA COYLE: All right, thank you.

A baby was declared brain dead in a Canadian hospital and, because donation of his heart was being considered, he was transferred to a hospital in the United States. In the U.S. hospital, he was tested and found to be alive. This was reported in the "New England Journal of Medicine" in 1989.

Similar reports keep appearing in newspapers, including the following:

Seattle Post-Intelligencer, January '89: A Yakima, Washington woman who doctors once said was in a state of "cerebral death," emerged from a deep, five-month coma two to three days after delivering her baby.

The Modesto Bee, October '89: A few days after a doctor asked Jennifer Keough's parents to donate the teenager's organs, the girl scratched out a misspelled but coherent message, "I wat to tak to my mom." When her mother arrived at her hospital room in Hollywood, Florida, Jennifer waved and wrote notes to her. Because the respirator was connected, she could not speak.

Kansas City Times, February '75: A wink of the eye saved S. William Winogrond just as a surgeon was preparing to remove his kidneys and eyes. He is fully recovered.

When cases like these are reported, embarrassed physicians often dismiss them as "misdiagnoses." The case of baby Luis Alvarado, however, cannot be swept away so easily. Although the public is constantly reassured about "death" based on brain criteria, the Alvarado case makes clear that something is terribly wrong.

Baby Luis Alvarado was born on September 6, 1989 in New York City. He looked like any other baby. He was fed and his weight gain was normal. He urinated and moved his bowels and needed diaper changes and bathing -- just like any other baby. His blood pressure, body temperature, and skin color were all normal.

Despite all these signs of life in baby Luis, a neurologist declared him "brain dead" two days after his birth. A week later, the same neurologist retested him twice and again declared him "brain dead." Because of this diagnosis, the parents were told by the hospital that they must obtain a court order to continue treatment for the baby.

A court-appointed neurologist, Dr. Eviatar, testified on October 10, 1989 that she had tested baby Luis, using the "guidelines provided by the Task Force for the Determination of Brain Death in Children," and baby Luis was comatose, he had fulfilled these criteria, and was thus "brain dead."

On October 18, 1989, the court ruled that baby Luis was dead and that life support could be removed. After appealing, the parents received permission from the court to have a doctor of their choice look at the baby. Their doctor said that the baby was definitely alive. The day after their doctor made that statement, the hospital, in defiance of court orders -- because the tests can be harmful -- brought in another doctor, Dr. Peterson, to retest the baby. Based on Dr. Peterson's findings, the hospital reversed itself in court, stating that the baby was now not "brain dead."

This was not a case of error in the physicians' testing. Luis Alvarado, a living baby, was pronounced dead because he met all the criteria of the guidelines for the Determination of Brain Death in Children, including being in a coma. These guidelines were presumably used with the 143 organ donors in 1988 who were less than five years of age and the 184 donors in 1989 of that age group.

The Task Force which set up the guidelines for children provides a remarkable exercise in semantics. In its report, the Task Force begins by endorsing this statement: "An individual who has sustained irreversible cessation of all functions of the brain, including the brain stem, is dead." Then, illogically, the Task Force requires that the patient not have too low a temperature or blood pressure for age.

A child who is able to maintain a normal, or near normal temperature or blood pressure cannot be "brain dead." The hypothalamus of the brain is the natural thermostat. The medulla of the brain controls blood pressure. In its guidelines, therefore, the Task Force is insisting that the child must have some functions of the brain when the child is declared "brain dead" because of no function of the brain.

That illogical requirement was made "logical" by a feat of semantics. The Task Force simply defined what would be considered an "absence of brain stem function." Any function of the brain stem that had the bad luck not to be included in the definition of the Task Force could henceforth be disregarded as a function of the brain.

The Task Force should not be completely blamed, however, for assuming that this nonsense would take wing. Who, for example, would quarrel with the success of the President's Commission for the Study of Ethical Problems in Medicine and Biological and Behavioral Research?

In its 1981 report, "Defining Death," the Commission had urged the passage of a Uniform Determination of Death Act. The UDDA allows death to be pronounced when there is, "irreversible cessation of all functions of the brain, including the brain stem." The UDDA became law in many states. Comatose patients whom nobody would have dreamed of calling "dead" 20 years ago, are now being declared legally dead in those states.

If the President's Commission had promoted a law that said that death could be declared when there is, "irreversible cessation of all functions of the eye, including the optic nerve," it would have been given short shrift. Everyone knows that nonfunctioning eyes are not equal to death. Most people have not objected to the UDDA's formula -- "death equals nonfunctioning brain" -- because hardly anyone knows enough about the brain to come up with a logical objection. That would include the medical profession. A 1989 survey of doctors and nurses who were likely to be involved in organ transplantation showed that 65% of them did not know the medical and legal criteria for "brain death."

The new definition of death -- "brain death" -- is based on a new philosophy which claims that certain comatose people may be regarded as dead. Objections have not been raised because most people do not yet realize that it is a philosophy. The public is under the false impression that doctors have scientific proof that a comatose patient with a nonfunctioning brain is dead. Some doctors wish to expand the new philosophy of death so that other categories of patients may be declared dead; for example, anencephalic babies, vegetative patients, Alzheimer's patients, etc.

The idea of considering the comatose as dead was first presented in 1968, one year after the first successful human heart transplant, in the "Journal of the American Medical Association." This article, "A Definition of Irreversible Coma," was by the Ad Hoc Committee of the Harvard Medical School. The Committee presented no scientific data to justify translating "coma" into "death."

After the Harvard criteria were published by the Ad Hoc Committee, there was much discussion of the new philosophy of death in the medical literature. Shortly thereafter, several states passed laws allowing death to be declared using neurological criteria. This is perhaps an example of the frequently repeated dictum, "All social engineering is preceded by verbal engineering."

In 1974, Willard Gaylin wrote in "Harper's Magazine": "The problem of euthanasia is well on its way to being resolved by what must have seemed a relatively simple and ingenious method -- the difficult issues of euthanasia could be evaded by redefining death." Just a few years after Gaylin's statement, the UDDA became law in many states.

A patient may be declared legally dead according to the Uniform Determination of Death Act even though: The patient's heart is beating; he has circulation and respiration; he sweats and urinates; he has recordable blood pressure; the patient is turned to prevent bed sores; he is suctioned to prevent pneumonia, etc. No one, though, has explained how a corpse can get bed sores or pneumonia.

In truth, from the patient's point of view, there is no need for a new definition of death. When a patient's brain has been grossly damaged, the patient dies very quickly. Only in the rarest of instances have such patients lived beyond a few days. Dr. David H. Ingvar states: "The mean period of continuing activity of the heart is only three to five days. Total brain death is not a prolonged state and, of itself, will never be a major medical or economic burden to society."

Since such comatose patients die quickly despite the assistance of a ventilator, there is no substance to the claim of the President's Commission that modern technology has created a great need for a new definition of death. It was because many legislators were convinced that there was such an urgent need that many states accepted the UDDA.

There are very puzzling omissions in the recommendations of the President's Commission. This is a very important statement that I am going to make now: In the President's Commission's report, it states, "The dead do not autoregulate." Now, autoregulation includes control by the brain of temperature, heartbeat rate, hormone levels, salt and sugar levels, blood pressure, etc. These functions persist longer than other functions of the brain in comatose patients who are being assessed for brain death. To avoid making false declarations of death, the testing of autoregulation would seem to be mandatory. Strangely, however, the Commission did not recommend that these functions be tested.

The Commission presented a long list of caveats and tests of the brain. Its recommendations, however, were diluted enormously by the statement: "The 'functions of the entire brain' that are relevant to the diagnosis are those that are clinically ascertainable." The clinical tests which the Commission recommended are the following:

* ice water in the patients' ears to see if their eyes move;
* cotton touched to their eyes to see if they blink;
* shining a light in their eyes to see if their pupils constrict;
* twisting the patients' heads to see their eye movements;
* putting a tube down the trachea to see if they cough;
* disconnecting the ventilator to see if they breathe on their own.

The first five are tests of brain stem reflexes. Besides these reflexes, only one brain stem function was recommended for testing. The Commission did not recommend that the jaw reflex and the snout reflex be tested, although the collaborative study -- that was the largest study of brain death -- had shown that these two reflexes were likely to persist longer than the reflexes that were recommended. No reason was given for excluding the stapedial and other brain stem reflexes.

The Commission's recommendations are somewhat like a game of "Let's Pretend." Let's test a few reflexes and pretend that the whole brain cannot function. Let's test for a few drugs and then pretend that there are no drugs involved. It is virtually impossible to eliminate the presence of every drug by blood testing; there are thousands. Let's take the patient off the ventilator and pretend that he does not need the ventilator to counteract inadequate pulmonary function. Patients with this condition can be harmed if taken off the ventilator. The condition has several causes, including trauma.

Unlike the children's game of "Let's Pretend," the Commission's recommendations create grave risks. That the Commission would countenance such hazards would suggest that they perhaps had a greater interest in producing a large pool of organ donors, rather than in protecting critically ill, comatose patients.

Medical experts testified to the Commission that the risk of mistake in a competently performed examination was "infinitesimal." The medical experts were evidently wrong. If the Bayesian probability theory were applied to the data that are presently available on brain death criteria, the theoretical risk of error "would hardly turn out to be negligible, let along infinitesimal." That quote is from Dr. Shewmon.

There are recent reports in the medical literature of patients who recovered fully after having met all the clinical criteria for brain death. These recoveries would not have been predicted by the President's Commission, which stated that, "The published criteria for determining cessation of brain functions have been uniformly successful."

Continuing of brain function in those who are supposedly brain dead has been discussed in several medical journals, and I have those listed at the end of this paper. Wetzel, and others, observed some unusual reactions in a donor undergoing organ removal. The records of nine other donors were then studied. In all 10 cases, as soon as the scalpel cut into the body, the blood pressure and the heart beat rate rose dramatically. These changes should not have happened since the entire brain of these donors supposedly could not function. Such changes in pressure and heartbeat rate occur in other patients undergoing surgery if they are not given enough anesthesia. Comatose organ donors are not given any anesthesia, although they are given muscle paralyzing drugs to prevent movement during organ removal.

The same reactions were seen in six brain dead donors by Conci, et al, who state: "The rises in heart rate and blood pressure were always related to the application of a specific surgical stimulus and vanished immediately after it was stopped."

The largest study of brain death, the Collaborative Study, reported on 503 patients over a two-year period at nine prominent hospitals under the auspices of the National Institutes of Health. An autopsy was done on about half of the patients who died during the course of the study. In 60% of the cases destruction throughout the brain could not be found. Forty-three percent of the patients who met the Harvard criteria did not have such brain destruction. In 10% of the cases, no abnormality of the brain could be found by direct visualization or observation under the light microscope.

None of the brain death criteria are based on data that are scientifically valid. The same is true of various tests which are supposedly "confirmatory" of "brain death." These would include the EEG, the bolus blood-flow tests, ultrasound pulsations, PET scans, etc.

Not only have the clinical criteria for brain death never been shown to be valid, but, according to the Bayesian probability theory, there is an inherent impossibility of validating them. In light of this, some have suggested that angiography be used to test for brain death. Angiography tests for blood flow to the entire brain. A dye is injected into the blood vessels and shortly thereafter the brain is x-rayed. Angiography can be toxic and may stop blood flow to the brain and could even cause death.

ASSEMBLYWOMAN FORD: Ms. Coyle, may I ask you a question? You are talking about some very specific medical conditions and criteria. Aren't those criteria to be worked out in the regulatory process, as opposed to during the legislative process?

MS. COYLE: What I am trying to point out is, contrary to what the doctors who have just testified have said, what they are doing right now in other states which have these bills, under accepted medical standards, is very dangerous. I can give you several examples.

ASSEMBLYWOMAN FORD: Are you a physician?

MS. COYLE: I am not, but I have a degree in science, and I--

ASSEMBLYWOMAN FORD: No, you don't have to be qualified or anything before this Committee. I am just curious.

MS. NIEMEYER: I forgot to announce it, but she is a former biology teacher, plus being our Medical Research Director.

ASSEMBLYWOMAN FORD: So basically you are offering the testimony as a way of rebutting the earlier statements made by some of the physicians?

MS. COYLE: Yes. Giving such a dangerous test when all that need be done is to wait a few days, is not justified. If the patient's brain is grossly damaged, his/her heart will stop beating in a short time. The angiogram would be given not for the patient's benefit, but rather for the benefit of those who need organs, those who wish to do research, or those who would benefit financially from the premature death of the patient.

A number of reports, moreover, show that brain function may continue although angiography indicates no blood flow to the brain. All of these are-- I have testimony in the back.

Rabbi Shamuel Blech points out: "There is no diagnostic method for determining when total lysis (liquifaction of the brain) has occurred, nor has total lysis ever been observed upon autopsy. Although the neurological causes are obscure, there is strong reason to believe that cardiac activity ceases long before total lysis could possibly occur." In the spring 1989 edition of "Tradition," Rabbi Bleich presents an analysis of Jewish law demonstrating that a declaration of death based solely on brain criteria is not acceptable in the Jewish tradition.

Those who embrace the philosophy that brain death is equal to death of the person frequently mention the fact that a heart can be removed from the body and, if properly maintained, may continue to beat outside the body for a considerable period of time. Although this is true, it is not a valid argument. Most people are aware that people have lived with mechanical hearts for months. It is therefore not the organ of the heart that much be present and functioning, but rather the vital function of the circulatory system, which is part of maintaining the unity of the body.

Pope Pius XII made a clear statement in the following teaching: "But considerations of a general nature allow us to believe that human life continues for as long as its vital functions -- distinguished from the simple life of organs -- manifest themselves spontaneously or even with the" -- I repeat this -- "or even with the help of artificial processes."

It would appear, according to Pius XII, that a patient deemed to be brain dead who is breathing with the help of a ventilator, is alive. Respiration is a vital function carried out only by someone who is alive. The ventilator -- less properly called a respirator -- moves air. A ventilator can cause air to move in and out of the chest of a corpse, but it can never cause a corpse to respire. In a corpse there cannot be any respiration -- exchange of oxygen and carbon dioxide.

The President's Commission viewed the brain as the primary organ or the regulator of the body's integrated functions. The Commission theorized that a patient who does not exhibit certain brain functions has ceased to exist as an integrated entity. From this philosophy regarding the brain, the Commission rationalized that certain comatose patients could be declared dead even though they show many signs of life.

Now, this next part is very important, and I would like your attention: The Commission -- the President's Commission -- deviated markedly from this philosophy when it made its recommendations for "brain death" testing. The Commission advocated as "relevant" the testing of five reflexes, although these reflexes have no integrative function. In contract, brain functions that are integrative were not recommended for testing. In other words, the Commission said, "We are saying they are dead because a person who is brain dead can't integrate." And then, when it came time to make the recommendations, they ignored the integrative functions of the brain, and all they offered were reflexes. And that is what doctors are doing now. They are testing mostly reflexes, not the integrative functions of the brain.

ASSEMBLYWOMAN FORD: Ms. Coyle, I don't mean to cut anyone off, but your two colleagues also want the opportunity to testify. I would like to--

MS. NIEMEYER: I am not going to be speaking, and--

ASSEMBLYWOMAN FORD: But there are many other people who have been waiting patiently all day. I have already allocated 20 minutes to your speech alone, so I--

MS. NIEMEYER: She is almost--

MS. COYLE: Actually, I am not going to read all of it. I am almost finished.

ASSEMBLYWOMAN FORD: I would appreciate it if you would just summarize it. I think we know where you are coming from, and the philosophical difference--

MS. COYLE: Okay. I just have three paragraphs that I want to read that are very important:

The President's Commission is not alone in this respect. Omission of testing of integrative functions is virtually universal. Even the Harvard criteria for brain death -- which are supposedly strict criteria -- omit the testing of the brain's autoregulatory functions.

It is evident that when the integrative functions are tested, very few patients may be declared brain dead. This was made clear by the Collaborative Study's assessment of the Japanese criteria for brain death. These criteria require an abrupt fall in blood pressure. Control of blood pressure is one of the integrative functions of the brain. Only 4% of the 503 patients in the Collaborative Study could be considered brain dead when an abrupt fall in pressure was required. if the testing of other integrative functions of the brain had also been required, the percentage would undoubtedly have dipped below 4%.

Perhaps least understandable is the failure to require testing of the brain's control of the body's hormonal system -- endocrine system. That omission is remarkable because the hormonal system itself regulates and integrates the body by means of hormones -- chemicals released into the blood by glands. The hypothalamus of the brain greatly influences this hormonal system.

The hypothalamus may continue its integrating function even when there seems to be no blood circulation to the brain. Shrader and his colleagues reported that hormonal functioning continued in six patients, although angiography indicated no blood flow to the brain. They concluded that circulation "too small to be demonstrated by angiography was maintained."

I will stop there. May I include this written testimony in the transcript?

ASSEMBLYWOMAN FORD: In the written transcript, sure.

Mr. Tomicki, would you address perhaps just your recommendations, or specific changes, in light of the time.

MR. TOMICKI: I am going to do that, Madam Chairman.

This morning I was shocked and stunned, and yet delighted, to hear Senator Ambrosio use the big "D" word relative to this issue. I was excited because it is what we have been kind of arguing for almost two years now. If we go back to his testimony, he used the words, "the brain is destroyed." The New Jersey Right to Life never took that position that we were looking for a standard where the brain required basic destruction. We kept saying, "incapable of ever functioning again."

But, if the sponsor of the bill -- and I cannot conceive that Senator Ambrosio would ever say anything he didn't mean -- came forward here today in support of the bill, using it not once, but twice-- He said, "brain destruction," and that is the crux of the issue. No one should be declared dead until the circulatory, respiratory, and brain, including brain stem, are, in fact, incapable of functioning and are thereby destroyed.

So, if the sponsor of the bill used the word "destroyed," then put that word directly into the bill. We could support that.

In addition to that, we would recommend that you would add language-- Mr. Elmer Matthews, one of our learned colleagues, used the comment that "coma" does not justify termination of one's life. So we would like to see an amendment in the bill that said: "No one shall be declared dead who is in a coma." If you added that, we could support it.

Now, as to Commissioner Armstrong's encouragement on the religious exemption, as the bill currently stands, you can have a situation where you will have two people in the same health care institution, in the same room, with the same pathology. One has a set of religious beliefs, the other has none. One will be alive, and one will be dead. That is just patently ridiculous. So, therefore, we would recommend, since part of the consensus that has been arrived at-- In putting in this religious exemption clause, make the severability clause that you have in this particular proposed legislation direct that if that religious exemption clause is stricken from the bill as a matter of court litigation, then the entire bill should go down.

On line 32, page 1 of the bill, where you use the phrase, "currently accepted medical standards--" Several of the doctors testifying here have used the word "scientific." So we would encourage that you say, instead of "currently accepted medical standards," you would have the words, "scientifically valid medical standards," because it is science that we are talking about, so when you test a reaction it will always come out the same way. Water always boils at the same temperature. Water always freezes at the same temperature. So you must have scientifically valid medical statements.

Lastly, the immunity section must be removed. How many of us in this room would go to our auto mechanic and get a redoing of our brakes on our automobiles, or a redoing of our transmissions, and then when we went to pay him, he said, "Well, if I have done this based on accepted mechanical standards, you will please give me immunity in case I screwed up--" It is patently false to put this out here this way, and it must be removed.

And finally, just for the record, if you want to see it, there is an article in Tuesday's New York Times which talked about surgery, a new frontier; suspended animation, removing the person down to a near death state, mimicking many things that will be in these currently illusionary, medically accepted standards. We are buying a pig in a poke if we buy this legislation, and we sincerely recommend that you consider the four changes we made. Then our organization could seriously consider supporting the bill. But at this time, on behalf of our over 52,000 members, we oppose both bills.

ASSEMBLYWOMAN FORD: Thank you. Dr. Ross?

STEVEN ROSS, M.D.: Madam Chairman, members of the Committee. My name is Steven Ross. I am the Director of the Southern New Jersey Regional Trauma Center at Cooper Hospital. I am speaking to you as a practicing trauma surgeon, and I treat injured patients who have fallen under the umbrella of Assembly Bill No. 1413.

I fully support the concept of a law to provide further legal background and definition for the declaration of death by neurological criteria. This bill could fulfill that need. There are several portions of the proposed bill which I feel I must oppose.

Considerable effort has been spent to find a scientific basis for the determination of death. This led to the development of criteria not only for the determination of cardiopulmonary death, but also for the determination of irreversible brain death. The majority of this bill does service to that effort. Sections 5. and 6., however, are in direct contradiction to the scientific approach, by making death the subject of religious or moral opinion.

At the Southern New Jersey Regional Trauma Center we see approximately 1800 injured patients a year, of whom approximately 500 have severe brain injuries. Although the Trauma Center's treatment of severe head injuries is designed to prevent irrevocable neurologic death, on a yearly basis 18 to 30 patients eventually progress to that end. It is extremely rare that young adults who most frequently suffer these major injuries have discussed their feelings regarding brain death with family members. We therefore will be faced with a situation where other individuals, such as family members or religious leaders will impose their will and their perceptions of death on the patient.

How is a physician to be sure whether a family member actually has a knowledge regarding the patient's personal religious beliefs or moral convictions, or whether it is extrapolated from their own beliefs? In addition, how can the physician be certain that the objection to the pronouncement of brain death stems from these personal religious or moral beliefs, or from the normal response of any individual to try to delay or prevent the death of a loved one? In my experience, the majority of objections to the pronouncement of brain death from families have come when the individuals were uneducated with regards to the concept, or were in the throes of the normal grief response and desired not to see their loved one passed on.

Under this law, those individuals who meet the criteria for pronouncement of neurologic death, and because of religious or moral objection, must be maintained for a prolonged period of time on life support, and will impose a serious burden on an already overburdened tertiary medical care system. They will require maintenance in intensive care units. At this point, New Jersey's existing tertiary care hospitals, particularly the trauma centers, do not have adequate critical care facilities to provide for the number of patients requiring critical care. For every patient who is maintained on life support after meeting the criteria for neurologic death, other patients who might well benefit from such intensive care and return to functional life in society, may be denied such care. This situation already occurs occasionally, even without the added burden of maintaining these living dead.

With the approach of rationing of health care resources, this may further reduce the resources available to the living. The care required for these patients is extremely taxing, not just economically and resource-wise, but emotionally on health care staff, particularly if it interferes with, or is perceived to interfere with the care of salvageable patients. Who is to pay for such care? Who will assure that the resources used to care for these irreversible, unsalvageable patients will not be taken from those who may remain alive and functional?

In the current climate of cost containment in health care and priority setting in expenditures of health care dollars, as well as the resource allocations required in the triage of health care -- intensive care settings -- this is the most nonproductive use of the limited resources that could be envisioned. This bill represents one step forward and three steps back in the development of rational determination of death standards. On one hand, it endorses a rational and scientific approach to death pronouncement, but on the other rejects it for an emotional approach.

If sections 5. and 6. must be retained, I urge you to reject this measure. Without those sections, I would endorse it wholeheartedly.

ASSEMBLYWOMAN FORD: Thank you, Doctor. Denise Payne?

DENISE A. PAYNE, R.N., M.P.A.: Assemblywoman Ford and members of the Committee: Thank you for allowing me the opportunity to speak to you today. I regret that the condition of my voice is going to limit my comments to those which are the most germane.

My name is Denise Payne. I am the Executive Director of the New Jersey Organ and Tissue Sharing Network, which is a federally certified, State-approved organ procurement organization--

ASSEMBLYMAN NAPLES: Denise, excuse me. They are having difficulty hearing you in the back.

ASSEMBLYWOMAN FORD: She can't talk any louder. Do you have written comments? (no response)

MS. PAYNE: I will try to speak as loud as I can. We are a State-approved and federally certified organ procurement organization, which is responsible for the recovery of organs and tissues for transplantation.

The Network is opposed to the passage of Assembly Bill No. 1413, known as the New Jersey Declaration of Death Act. The intent of this Act is to legally define death by statute. While New Jersey needs a Definition of Death Act, there are many problems associated with this proposed legislation.

If passed by the Legislature, the Network's ability to recover organs would be seriously impaired. New Jersey's rate of organ recovery per million population is currently one of the lowest in the country. Sections 5. and 6. of the bill cause the greatest problem for the Network. These sections would restrain a physician from declaring death based on neurological criteria if that diagnosis was contrary to the patient's religious or moral convictions.

All organ donors must be declared brain dead before solid organs can be recovered for transplantation. This bill would allow individuals outside of the medical community to override a medical diagnosis which is based on scientific findings. That would not only burden the family with making the diagnosis of death, but would strain already scarce health care recources and add significant costs to the health care system. With advancing sophistication in medical technology and care, the ability to sustain the bodily functions of a brain dead individual will markedly increase.

Additionally, this proposed legislation is not consistent with the Uniform Definition of Death Act as proposed by the Uniform Law Commission and adopted by over 44 other states. We believe that the current wording would create more problems than the bill would solve and may lead to confusion and a decline in life-saving organ recovery.

I thank you for this opportunity. If there are any questions, I would be happy to answer them.

ASSEMBLYWOMAN FORD: Thank you. Are Frank Kowar and Joseph Bush here? (affirmative response from audience)

JOSEPH E. BUSH, JR.: Thank you, Madam Chairwoman. Members of the Committee: I am Joseph Bush, and this is my colleague, Frank Kowar. We are members of the Board of Church and Society of the Northern New Jersey Annual Conference of the United Methodist Church. There are two conferences in New Jersey.

ASSEMBLYWOMAN FORD: Again, I would ask you to speak up a little bit. These microphones are for recording purposes, not for sound projection.

MR. BUSH: Certainly. I would like to address my comments primarily to the New Jersey Advance Directives for Health Care Act. I address you this day as an individual citizen of the State of New Jersey, as well as a member of the United Methodist Church.

There are 150,000 United Methodists in New Jersey, and we have 10 retirement homes in the State, all but one of which provide medical care for our aging residents. The Methodist homes have endorsed the bill for advance directives.

The United Methodists affirm the right of individuals to make decisions concerning their own medical treatment. Our Social Principles -- which appear alongside our "Articles of Faith" in our authoritative "Book of Discipline" -- read as follows:

"We recognize the agonizing personal and moral decisions faced by the dying, their physicians, their families, and their friends. Therefore, we assert the right of every person to die in dignity, with loving personal care and without efforts to prolong terminal illnesses merely because the technology is available to do so."

We would therefore tend to be supportive of any measures by the State to acknowledge, safeguard, and enforce the right of individuals to choose concerning their medical treatment. Recognition of the validity of so-called "living wills" is essential for legally securing this moral right of the individual.

This is not to say, however, that in New Jersey among United Methodists there is universal support for the New Jersey Advance Directives for Health Care Act being considered right now by this Committee. At the 1989 session of the Northern New Jersey Annual Conference, a resolution was passed endorsing the version of this bill that was then before the Legislature. At our conference session, there was considerable debate. The house was quite evenly divided, and a standing vote was required for the final vote. At issue for us was not whether individuals and their families should be the ones making the medical decisions or whether "living wills" should be "legal." In fact, there seemed to me to be a broad consensus -- and, indeed, very strong feelings -- in support of living wills and a patient's right to decide. At issue for us was whether this particular bill strengthened or weakened an individual's right to make medical decisions, as that right has so far been defined by decisions of the State Supreme Court. In particular, two aspects of the Advance Directives Act were troubling to us: 1) stricter criteria used to justify the removal of artificial hydration and nutrition than other types of medical treatment; and 2) the provision for the exemption of religious institutions.

There is nothing, as far as I know, in Methodist moral teaching that would suggest that artificial hydration and nutrition are categorically different from other types of medical treatment. Moreover, it seems to me that to impose treatment -- including artificial hydration and nutrition -- against a patient's wishes is to violate that patient's dignity and, indeed, his or her physical person. I cannot see how freedom of religious expression can confer on religious institutions the right to commit what to my mind would be battery.

If a patient's right to choose concerning medical treatment is to be adequately protected from infringement, all comparable medical institutions in the State should be subject to the same policy, and that policy should be free from distinctions of medical treatments based on a particular group's moral valuations of such treatments.

Furthermore, during that floor debate at our 1989 session, concern was expressed for the likely majority of people in this State who, despite all educational efforts, will not provide their physicians with advance directives. Will their right to refuse treatment be respected if this bill becomes law? The bill currently before this Committee states that no presumption is being hereby established regarding the treatment of those individuals who will not have executed advance directives. But in the actual decision-making of institutions and physicians will there not be a tendency to treat such individuals more aggressively? Certainly I think this will be the case concerning artificial hydration and nutrition. Paragraph b. of section 16. states:

"Nothing in his Act shall be construed to provide authorization for the health care representative, or any other individual acting pursuant to this Act, to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to sustain life in the absence of explicit instructions to that effect in the patient's advance directive."

For us, this is a very disturbing paragraph.

At the last session of our Northern New Jersey Annual Conference in 1990, with these same concerns and reservations in mind, the Conference did not discuss this bill to either endorse it or condemn it. Instead, we passed a rather insipid resolution calling for our churches to study the issue. This is not because we are unconcerned. Rather, it is because we are deeply concerned, but our feelings on the matter are mixed.

To summarize my own sense of United Methodist opinion on this matter in the Northern New Jersey Conference:

1) We strongly affirm a patient's right to decide concerning medical treatment;

2) We support the use of advance directives and wish to see them consistently enforced by law;

3) We remain concerned about the protection of the right to choose in those cases where there is no advance directive;

4) We do not distinguish morally or theologically between artificial hydration and nutrition and other forms of treatment; and

5) I should at least hope that our United Methodist institutions would not want to be exempt from the State's policy in this matter, and I do not think it wise to allow for such exemption.

I would also like to say that although it may seem that New Jersey constituents are polarized on these issues, and that religion energizes and complicates this polarization, there does seem to me to be a larger ecumenical consensus appaearing in these matters. Although I am a Methodist, my own position which I have here outlined has been greatly informed through my reading of Roman Catholic moral theologians. Most recently, a joint United Methodist/Roman Catholic statement on this subject was issued after three years of dialogue. Entitled, "Holy Living and Holy Dying, the statement reads:

"We affirm that the obligation to employ life-sustaining treatments ceases when the burdens -- physical, emotional, financial, social -- for the patient and the caregivers exceed the benefits to the patient. The application of excessive procedures, sometimes encouraged by the ingenuity of modern medical technology, does not reflect good stewardship because it does not serve the purpose for which God gave life."

Also recently -- and this is more of a comment having to do with the New Jersey Declaration of Death Act -- the Orthodox Chief Rabbinate in Israel issued "Directives" allowing for the determination of death on the basis of neurological criteria. It was translated and reprinted in "Tradition" in the summer of '89. New Jersey policy is divided enough by partisan politics. It seems to me a shame to let it be divided further by partisan religion, especially at a time when the religious traditions concerned may themselves be growing less divided on the issues in question.

In closing, I would like to thank the Committee for hearing me. I would also like to thank Mr. Armstrong and the Bioethics Commission for their excellent work on this and the other vital issues facing them and us. I sincerely hope that the Commission will be adequately funded.

ASSEMBLYWOMAN FORD: Thank you. Mr. Kowar, is there anything you would like to add to that?

FRANK W. KOWAR: Yes, Madam Chairman. I would like to read into the record a portion of a brief of the General Board of Church and Society of the United Methodist Church of the whole United States. It is an amicus curiae in support of the petitioners, Lester L. and Joyce Cruzan, the parents and co-guardians of Nancy Beth Cruzan. This was presented to the Supreme Court of the United States in October of '89. It is further support of what Joe has stated in his remarks here concerning the hydration and nutrition:

"In particular, amicus believes this Court's evaluation of Nancy Cruzan's interests in the withdrawal of artificial nutrition, and the State's interests in prolonging life, should reflect three principles fundamental to our tradition and conscience:

"First, life should not be assessed in purely medical terms. Life and death, as amicus understands them, are an integration of the spiritual, emotional, and physical aspects of being.

"Second, the goal of prolonging the physical life of the body at all costs, in whatever form, is radically inconsistent with amicus' understanding of the proper respect of life and for death.

"Third, choices about how best to cope with the natural ending of life are, at bottom, intensely personal and family decisions, best made within the confines of the family."

When, as in the present case, the choice of the individual is not known with certainty, the family should play a critical role as a surrogate for the individual. Government intrudes deeply, and without sufficient justification, into the sanctity of the individual and the family when it seeks to dictate the standards by which these profoundly personal and family decisions must be made, and when it refuses to afford the family its proper role in making these decisions.

"Health care is inadequate when it fixes its attention solely on the body and its physiological functions as is any religion that focuses its interest entirely on the soul."

"From the Health Care Delivery and Policy Statement of the 'Book of Resolutions of the United Methodist Church,' adopted in 1980 and in the 'Book of Resolutions,' page 240, the 1988 edition:

"Indeed, to ignore the spiritual or mental dimensions of a person while addressing physical injury or illness as is scientifically -- is scientifically irresponsible, as it is religiously irresponsible to treat spiritual needs and ignore the physical and mental dimensions of the human body. These deeply rooted principles have particular application in the issue before this Court. Evaluation of the interests at stake should not be premised on an impoverished understanding of the meaning of health and life. A failure to acknowledge that life encompasses the integration of physical, mental, emotional, and spiritual being, could well eschew the analysis by improperly dimensioning this Court's assessment of the legitimacy of a person's decision to forego life prolonging treatment in the event of permanent loss of consciousness.

"Conversely, failure to acknowlege these traditional understandings may result in an exaggerated assessment of the strength of the State's interest in preserving elemental physical functions, notwithstanding the permanence of the condition and the contrary wishes of the patient and the family."

Madam Chairwoman, we thank you very much for allowing us to present these, and I don't envy the Committee their work in trying to sort all of this out.

ASSEMBLYMAN NAPLES: May I have a copy of that, or the citation? I would like very much to read it.

MR. KOWAR: Yes.

ASSEMBLYMAN NAPLES: My number is in the book. I think anybody here can--

MR. BUSH: We also have a copy of the statement of the Chief Rabbinate, and an article about "Holy Living and Holy Dying," if you want that, and copies of my statement.

ASSEMBLYMAN NAPLES: Okay, but I want to read that, too. Thanks a lot.

ASSEMBLYWOMAN FORD: Andrea Augenbaum, New Jersey State Nurses Association?

ANDREA AUGENBAUM: Thank you, Madam Chairman. The New Jersey State Nurses Association will present written testimony to the staff. I am not going to read that testimony, because you have had a long day.

I just want to tell you that we support S-1208 and S-1211 as they are presented. We support the Commission's work. We were part of the group that brought about the Commission. We have a member on the Commission. There are other nurses who are members on the Commission. We have followed their work closely, and we support what they support.

If you decide that you do not want the religious exemption, we will support that, and live with that, too.

We need a bill. The nurses in New Jersey need a bill. What we are asking is that you pass a bill. Again, we support the Commission.

ASSEMBLYMAN NAPLES: Unamended?

MS. AUGENBAUM: Well, you could amend for the religious exemption. We would be okay with that.

ASSEMBLYMAN NAPLES: All right.

ASSEMBLYWOMAN FORD: Thank you. Is Mr. Cunningham still here, from the New Jersey Association of Health Care Facilities? (no response) Janet Marks?

JANET MARKS: Madam Chairman and Committee members: Thank you for waiting for me.

My name is Janet Marks. I am the Legislative Coordinator for Concerned Women for America of New Jersey. I am speaking on behalf of Marie Ransome, who is the State Director, who is not able to be present today.

Concerned Women for America is a national, nonprofit, public policy organization of over 700,000 members, which is dedicated to the protection and preservation of traditional family values and constitutional principles. In speaking for the State Director, I am here today representing 10,000 families and members of CWA of New Jersey, to speak in opposition to the above-listed "death" bills -- appropriately tagged -- that are being reviewed by this Committee. We oppose these bills because of the overall lack of respect for the sanctity of life.

For example: A-1413, the New Jersey Declaration of Death Act, or the brain stem death bill, declares comatose patients legally dead who otherwise are breathing, have a heartbeat, and normal blood pressure. This bill is lethal to the patient because the doctor involved is fully protected from any civil or criminal liability. Plus, a dying patient who is labeled "brain dead" could be prolonged on machines solely for the purpose of finding a suitable donor for his organs. The organs are then sold to another patient. I believe it is a case where those who are unable to protect themselves may fall open prey to the evils of society.

The living will bills allow starvation and dehydration of certain patients, especially the elderly and infirmed. These living will bills are not necessary. Right now in New Jersey a person can sign a power of attorney and appoint someone to make medical decisions for him when he is unable to do so. The present power of attorney, however, does not give sweeping immunity from liability, as do Assembly Bill Nos. 2514 and 16.

My own father-in-law, who recently passed away at the age of 66, almost died eight years earlier. I wonder if bills such as these were the law eight years ago, if my husband would have had those cherished years with his father.

As a doctor friend of mine recently said to me, "A doctor is not God. God appoints the time when a person is to die or to survive and live, not doctors." This message is applicable to legislators, as well, and quite appropriate in response to these "death" bills. Please consider this when voting on these bills.

Thank you.

ASSEMBLYMAN NAPLES: I just want to say that special interests are not God either.

ASSEMBLYWOMAN FORD: Thank you. Theresa Gleason? (no response) Ira McManus? (no response) Howard Nathan? (no response)

IRA McMANUS, R.N.: (speaking from audience) I am Ira McManus.

ASSEMBLYWOMAN FORD: Oh, I'm sorry.

MR. McMANUS: I am a registered nurse in the State of New Jersey, so I am speaking as a registered nurse, not necessarily representing anyone's views except for my own. I am kind of dismayed to see that the Nurses Association is supporting the bill. Apparently a lot of them have forgotten the fact that when they first went in as students perhaps, and saw that first patient who was maybe in a comatose state, with the horror that struck them at that time, knowing that a person had to be that way-- I don't think that any of us, in our student days, ever considered death as a sentence for any of these people.

I want to discuss first the living will bills. That is the generic term on them. First of all, I feel that they were misnamed, if nothing else, because they have nothing to do with the living and everything to do with the dying. Second of all, they are not wills at all. Third of all, they are death directives, as far as I am concerned. You are asking a person to make uninformed consent. This was mentioned earlier by someone else, but that is what it is -- uninformed. You are asking someone to sign a piece of paper to tell them about something that might happen seven or eight years down the road, and you are asking them how they feel about it today -- to make a decision for the future.

Also, another reason I oppose it is, the Euthanasia Society started the idea, which automatically causes concern and reservation at the onset, as far as I am concerned. Also, many patients do change their minds. People will change their minds. They fill out a bill and they may forget to change it like they do with wills. People might just not get around to it.

Also, there are some murky definitions. When you start talking about different aspects of artificial means and terms like "heroic measures," "terminally ill," "reasonable expectations," what do all of these terms mean? These terms change from time to time, and it is also different from person to person. It is going to be almost impossible to control this type of a practice. It will be malpractice suits galore.

Also, without a doubt, this is a form of euthanasia. I think someone pointed out that there are many ways to euthanize in our society. There is an active way, a passive way; a direct and an indirect; a voluntary and an involuntary way. Most certainly, this bill would have to be at least a passive way of doing it, and also that applies to the brain death bill, as we call it. The bill is leading us down a slippery slope of legalized euthanasia.

Now, it was not surprising to me to find that nursing homes and extended care facilities today endorse that. You just have to look past the surface on this. You have patients in nursing homes. You have people waiting to get in, who cannot get in at this point because many of the nursing homes are full. But you have a lot of people who in 1965, 1970, 1975 left their estates in a living trust, if you will, to be paid to the nursing home to take care of them for life. Maybe in 1960 it was $800 a month. The nursing home, in a sense, is taking a loss on that.

Well, lo and behold, we have Mrs. Jones down the road waiting to get in here, and her estate is going to leave $7000 a month. And Mrs. Smith around the corner there with the tube feed, is really not as valuable anymore. In fact, she is a direct detriment to the nursing home. Hence, the lady down the road can get it as soon as they unhook the tube feed, which will be allowed by the laws. And that goes for the death bill as well.

Why don't the insurance companies favor it? Simply because of money. Many of the grass roots bioethical committees also receive funds from the insurance companies. In fact, over $100,000 was given by the Prudential Foundation to the New Jersey Citizens' Bioethics Committee. Also, seven to nine seats on the Bioethics Commission were filled by members and supporters of the New Jersey Citizens' for Bioethics Committee. Furthermore, a former publicity person who for five years served on the New Jersey Citizens' Committee -- T. Patrick Hill -- who also testified before the Senate Judiciary Committee, is now the Director of Education for the Combined Right to Die and the Concerned for the Dying in New York City.

Also, insurance companies will refer, or start referring their clients to that institution that aggressively terminates the patients, rather than giving them the benefit of the doubt, thereby saving themselves millions and millions and billions of dollars in the future.

I want to talk about the death bill for a minute -- the New Jersey Declaration of Death Act, Senate Bill No. 1208. I have a question: Why are we trying to redefine death? It's funny, one of my daughters-- I took her to the hospital where I worked a couple of years ago, and I tried to explain a patient on a respirator, or a ventilator -- which is the proper term. She said, "Well, what's the matter?" I said, "Basically, this patient is dying." She said, "Well, what if you took him off the machine?" I said, "Well, that patient, with that particular problem would be dead." On the way home she was talking to my son, and she said, "I'll ask Dad." She goes, "Dad, is that patient just a little bit dead?" And I said, "No, you can't be a little bit dead. You are either dead or you are not dead. There is nothing in between." Until now. This is in between -- this bill here.

The only sure fact of yes, he is dead, no, he is not dead-- It puts this in the middle of a wide gray area, which we could all play around in.

I am a nurse. I work very closely with these patients. Dr. Ross, who testified earlier-- I happened to work in a hospital in the capacity of a nurse on a neurology floor for several years. I took care of hundreds, literally hundreds of Dr. Ross' patients. He is a very fine physician. Many of the patients -- I think he referred to numbers of 500 or so per year who were brain damaged or whatnot-- Many of the patients who are considered brain dead, or what we call now "essentially brain dead," or in a persistent vegetative state, which can all be used interchangeably-- I don't know who we are kidding by trying to say they cannot. But, a lot of these patients do come out of it. It doesn't take maybe three weeks. It might take six months. I have had patients come out of it in a year. In fact, a couple of instances were read about earlier by Pat Coyle up here, and I could give you a couple more:

Memphis Commercial Appeal: It says: Philip Cockerman (phonetic spelling), just as his liver was going to be removed-- A twitch of his foot saved his life.

Another one: Sherry Lockem (phonetic spelling), just before having her vital organs removed-- The 11-year-old girl was declared dead 20 minutes before, but moving fingers alerted the doctors that she wasn't dead.

In the "Journal of Clinical Neurophysiology," in 1988-- Seven patients who had been clinically brain dead, recovered. There were articles in there regarding that.

There were other ones, too. I am not going to go into a lot of this stuff here.

I have countless case histories myself of patients who are either considered brain dead or essentially brain dead or what they call now a DNR status, which allow, in many cases, a person to just take the curtain and draw it around a patient and let the patient die, because there is no interest in that patient anymore.

What we are doing now is-- We have a voiceless patient, or a voiceless human being. Up until now, in the State of New Jersey, we have allowed the patient to have some kind of input. This bill-- It has been suggested today by some physicians, as well as some other interested parties, to even take out that part of the bill. First of all, I don't support the bill one bit at all -- the way it is, or even any kind of death bill at all, because it is not needed.

Also, the malpractice-- The immunity obviously takes away the rights of the patient. It also takes away the rights of the living family, which perhaps has to live with the idea that maybe that wasn't impossible; maybe that person could have lived. Also, the bill doesn't spell out anything. It has no guidelines. It says in the bill-- Everybody behind me hopefully had an opportunity to read it. It says in there that it will be determined within 120 days after the enactment of the bill, and then the blanks will be filled in later. So you guys are going to pass a bill, perhaps, and then let them fill in the blanks later. That is absurd.

Also, it says you can amend it any way you see fit as time goes on. That is absurd. It is proposed to eliminate sections 5. and 6. Basically that would mean that the family is out of the picture in the whole process -- in the whole decision process whatsoever, 100%. In other words, don't get the family involved. Let the medical community decide what's best. That's wrong, too.

What is "brain death"? Now, I have listened today to everybody. I was here first thing this morning. I did not hear anybody prove scientifically-- I have yet to hear a scientific consensus as to what brain death is, because there isn't any. It's a myth. It is more appropriately called, maybe, "brain handicapped," maybe "brain disabled." It is interesting, because we do protect all the handicapped. We have ramps for the people in wheelchairs and whatnot, but we protect the handicapped. This person is handicapped. He is voiceless, handicapped, and what we are doing is proposing to terminate his life.

Basically what we are saying is that this person who is handicapped and disabled is society-useless, and therefore it is society-useless people's death. Since when is the state of dying equal to death? Now, we can prove that life and living is scientific-- We can prove that scientifically, but we cannot establish when brain death occurs scientifically, except in the absence of a heartbeat, the circulatory system, etc., because that is the only criteria whereby you can tell that the brain is not functioning. You need a brain stem in order to maintain a blood pressure. You need a brain stem in order to maintain circulation, to maintain a heartbeat. Therefore, if you have a heartbeat and you have circulation, you have life -- period. It's clean and simple.

ASSEMBLYWOMAN FORD: Mr. McManus, in light of the hour, may I ask you to try to wrap up and conclude your remarks?

MR. McMANUS: I do have a couple of other things. Also, there are a lot of drugs. It is interesting. This is a fact: You have a drug called Decadron, which is a steroid, which can be administered to a person. Basically it will, in a sense, dry the brain up a little bit to allow a little bit more room in the head. What happens is, if the brain is expanded it is pushing against the skull and the head, and you don't have enough room to allow circulation to take place in the head.

We have, coma scales we call them, the Glasgow (phonetic spelling) coma scale for example. The lowest you can get is a three; the highest is a 15. I had a patient where at 2:00 it was three, at 5:00 it was a 10, and at 7:00 it was a three again because of the administration of medicines. It responds very quickly to medicine. In the absence of a drug, for example, you could easily -- in some of these patients -- mimic your criteria, as you call it, for brain death.

You can't maintain temperature control if you are brain dead. An EEG-- I challenge, probably any doctor to really accurately read an EEG. I was told recently that there are only about 10 qualified specialists in EEG reading in the whole State of New Jersey. I am not sure if that is true or not, but that is what I was told. You can pick up any kind of interference anywhere, on a bed, on the vibration of the floor -- of an ice machine on the floor below -- or anything.

Organ transplants is one of the reasons why this is coming up, and I just want to draw up a quick scenario, and then I have a couple of other points to make. You have a 25-year-old female and a 65-year-old female, and they are both on ventilators and they are both considered brain dead. At that point they become dead. Neither of them, before that, is worthwhile to society at all. They are both dead. Well, lo and behold, when you pronounce them both dead, what happens is, the 65-year-old-- Let's say she has been on drugs, her kidneys are not that good, and everything else is not good. They will unhook her and she will become stage two of death, which is real death. Okay? She was dead. Now she is dead dead, rather than just dead. Well, the 25-year-old girl all of a sudden becomes of value to society now, because what does she have? She has usable parts. This sounds maybe almost out of this world, but it's true. She becomes of value to society now.

There are laws on the books in certain states now where they are proposing that you must take these organs out of people and sell them in order to defray the costs of the hospital bills of the uninsured. So we are approaching that. So that person becomes society useful again. Well, you are not going to pull that person off the ventilator, because she is useful to society. It's kind of scary. So the other lady becomes permanently dead, instead of just dead.

The other question is: If the person is really dead, why don't we just bury them? Why do we have to wait for their heart to stop beating?

I am concerned about the broadening of the definitions. We are going to start including Alzheimer's victims in this, and various degenerative and organic brain syndromes, and other persistent vegatative state patients will end up being in this type of thing. As I said, we are using essentially brain dead now as a criteria.

If there is any doubt whether a patient is dead, why don't we give the benefit of the doubt to the patient? What we are doing is trying to take that away. Why are we trying to redefine death?

One statement here-- Actually, I am going to continue, because I have a couple of other things to do here. We, as a society, should be uncomfortable with equating dying with death. Declaring a person with brain damage or a person who is brain handicapped dead does not make it so. Just saying it, doesn't make it so. The term "brain dead" in the future will become the ultimate label feared by the infirm and the elderly and the mentally handicapped, and their families. Just by calling a dying or a comatose patient dead does not make it so.

I heard someone here mention death with dignity. I want to read something. When a person is allowed to starve to death with dignity, as they call it, which is a--

ASSEMBLYMAN NAPLES: Life with dignity.

MR. McMANUS: Well, it is death with dignity. They are trying to prolong death--

ASSEMBLYMAN NAPLES: No, life with dignity; I'm sorry.

MR. McMANUS: You are trying to speed up death. You're saying it is life with dignity?

ASSEMBLYWOMAN FORD: Mr. McManus, the purpose of this hearing is not -- and I caution the Assemblyman also -- to have an interchange or an argument back and forth. We still have a few more people who have also waited all day to testify. Some of what you are saying is repetitious of what we have heard before.

MR. McMANUS: That's right, and I am--

ASSEMBLYWOMAN FORD: I respect your right to come forward and say it -- put it forth on the record. I just ask that you summarize your points, and conclude.

MR. McMANUS: I have about 10 lines to read, and then I have one paragraph to summarize.

ASSEMBLYWOMAN FORD: Thank you.

MR. McMANUS: This is a patient dying with dignity: His mouth becomes dried out, becomes caked or coated with thick material. His lips become parched, cracked, or fissured. His tongue becomes swollen and might crack. His eyes sink back into their orbits. His cheeks become hollow. His mucosal, or the lining of his mouth becomes dry and cracks, and also his nose-- His nose starts to bleed. His skin hangs loose and the body becomes dry and scaly. His urine becomes heavily concentrated, causing a burning of the bladder. The lining of the stomach dries out causing dry heaves and vomiting. He develops hypothermia and his temperature goes up. I have seen 108 degrees. His brain cells will begin to dry out, causing convulsions. His respiratory track dries out, giving rise to very thick secretions that can plug his lungs and cause death. Eventually the major organs fail, including his lungs, his heart, and his brain. Then death. Where is the dignity in that?

Concluding, what ever happened to dying a natural death? Isn't a dying brain really part of the process and a logical and natural occurrence? Why are we now proposing to abort the lives of yet another group of silent human beings?

Thank you.

ASSEMBLYWOMAN FORD: Thank you. Rita Riccardo?

RITA RICCARDO: Thank you. I appreciate being able to be here for just a few minutes. I will cut this short because I know you have had a long day. We have all had a long day. I appreciate your indulgence, because this is my first try at being a witness and giving testimony.

I represent the New Jersey Advocates for the Disabled. Since one must be in a coma to be called brain dead-- If you are in a coma we feel you are disabled, and we certainly feel as though we want to be somewhat of a spokesman for the disabled.

However, I would like to say that I don't envy you as a Committee with this tremendous decision before you. If one thinks, "I cannot be called brain dead because of my religious convictions, but the fellow next to me, well, he's dead-- It's too bad, but he didn't have any religious convictions on that." Or, if we don't have enough brain dead individuals, where are we going to get our transplants? That frightens me a little bit.

New Jersey Advocates are also particularly interested in a section of the bill -- the Declaration of Death Act bill -- which is the removal of medical liability, which could very well encourage medical discrimination against the poor and the disabled. They run the risk if medical liability is removed under the terms of this bill. As stated in section 7., lines 42 to 48: "A licensed health care practitioner," and so on and so forth, "pursuant to this Act, shall not be subject to criminal or civil liability or to discipline for unprofessional conduct with respect to those actions."

Now, added to this risk to the patient is the fact that brain injuries often require lengthy and expensive treatments. It is unfortunate, but they do. Hospitals may suffer financial loss from uninsured and Medicaid patients. The "New England Journal of Medicine" notes a significant association between monetary factors and an increase in the death rate of Medicaid patients by 6% to 10%. That is disconcerting information, especially regarding brain death, since there are definite economic incentives for declaring poor patients brain dead. For instance-- I am not going to tell you the story; I am going to let you read it, if I may. It is from a newspaper, and rather than read it--

ASSEMBLYWOMAN FORD: We will make it part of the record.

MS. RICCARDO: I would appreciate that, and I will give you this. It is simply about Pamela James from the State of Ohio, who was a 33-year-old welfare mother. She was apparently diagnosed within 25 minutes of being taken to the emergency room of a hospital -- St. Vincent's in Ohio. She was declared brain dead. Her parts were immediately disassembled. Apparently, after it was over they felt it might have been too soon. As the article goes, indeed, "Did Doctors Act Too Soon?" So, if I might leave this for you--

I'll just say a few little things about-- Needless to say, we feel that through the Declaration of Death Act bill, our society is given the power to write off disabled, comatose patients. This is inhumane and, as a group in this society, we ask the Committee to vote against this bill.

Now, on living wills, we are asking the same thing. They are being promoted in the media as giving rights. Actually, this is not true. Patients now have the right to reject or acquiesce to treatment. When they are not able to designate what they wish, their families-- Who is more interested than their families? They can consult with the physicians. The living will bills and advance directives bills will remove the say of the families, and will force the physician, even if it is against his best medical judgment, to follow the living will, no matter how old it may be.

Now, on the Federal level, just an interesting note: It is the Senate Finance Committee which has promoted a bill which requires hospitals and doctors to provide patients with information on living wills. Now, I'll tell you-- I hate to admit it, but am I getting to that point soon? I don't know if I go to a hospital if I want that kind of information. I want them to do the best they can for me. That is all I would be interested in.

The proposed requirement was tucked away in a deficit-cutting bill approved on October 13, 1990 by the Senate

Finance Committee. The bill provides that hospitals and doctors that did not comply with the requirement would not be able to treat Medicare patients, a major source, as we all know, for most health care providers.

The New Jersey Assembly Health Care Policy Study Commission held a hearing in Newark on October 9 of this year. Assemblyman James McGreevey said: "The goal of Medicaid reform is to improve access to care in addition to saving money." Several times during the proceeding, he noted that of the $2.2 billion spent on Medicaid in New Jersey, three-fourths of the money went toward the care of the elderly, the disabled, and the blind -- groups that make up just one-third of Medicaid.

The New Jersey Advocates for the Disabled is concerned in this atmosphere of cost savings that the savings will be made at the expense of our most vulnerable citizens -- the elderly and the disabled. And, we are all going to be there one day. We might be fortunate enough never to be disabled, but we will be elderly. We are very disturbed by the paragraph in Senate Bill No. 1211 and Assembly Bill No. 16, page 3, lines 17 to 26, which include: "Mental health institutions, facilities, or agencies, or institutions, facilities, or agencies for the developmentally disabled--" Now they are all going to get the big push for living wills. Has our society degenerated to the point that we have to kill patients to cut costs?

As I said, I appreciate what you, as a Committee, are trying to do. I would just hope that you will keep in mind to search for truth and righteousness. Thank you very much.

ASSEMBLYWOMAN FORD: Thank you. Gregory Millman?

GREGORY MILLMAN: My name is Gregory Millman. I am a free-lance journalist in New Jersey. I am here as a private citizen. I don't represent any group. I am very concerned about the New Jersey Declaration of Death Acts that are before the Committee.

Not long ago, the respected British television network, the BBC, sent a camera crew to the United States to examine brain death. About half a dozen brain dead people talked to the British journalists. They were mothers, husbands, children, fathers, secretaries, sailors, corporate executives, all leading healthy, happy, productive lives after having been declared brain dead.

For example: Dave Churchill pilots a riverboat in Alaska. He sustained an accidental head injury, and was taken to the hospital where doctors tested him for brain death.

ASSEMBLYMAN NAPLES: How soon afterward -- if I may ask -- did he pilot a boat after having been declared brain dead?

MR. MILLMAN: Well, within a matter of months, sir, is my understanding.

ASSEMBLYMAN NAPLES: The diagnosis was correct?

MR. MILLMAN: Well, obviously, it wasn't. The tests that were used were: they shone a light in his eyes; they put a tube down his throat; they squirted ice water in his ears, and so forth. He didn't respond. The doctor was convinced that he had a corpse on his hands. The interesting thing about this was that Dave Churchill later told the BBC about his experience. He said, "I could see them as plain as day." Now, this was a man who was passing the test for brain death. "I could hear them hollering at me. I could see them looking into my eyes. I could hear them hollering at the other doctors. There was no way I could respond. I couldn't move my lips. I couldn't move my eyes, nothing." Fortunately, Dave Churchill's doctor was not in any hurry to remove his organs. More time and more tests eventually did show that Dave Churchill was not dead after all. When the BBC caught up with him, he was swinging that big pilot's wheel, steering his boat around the bend of one of those majestical Alaskan rivers, with the mountains in the background. He said, "I love this river."

Well, Dave Churchill was lucky, because some doctors are in a hurry, and they don't take all of the pains that Dave Churchill's doctor took before they sign a death certificate declaring someone brain dead. There are about 30 different categories for brain death.

On March 6, 1988, the welfare mother we heard about briefly, Pamela James, went to the St. Vincent's Medical Center in Ohio, and the emergency room doctor conducted just a few of the tests that Dave Churchill had watched his own doctor conduct on him. The tests lasted less than five minutes. The doctor diagnosed brain death. Pamela was unconscious, of course, and she couldn't get a second opinion. Within hours, an organ procurement team removed all of her leg bones, her kneecaps, Achilles tendons, liver, kidneys, chest cartilage, and the main arteries to her heart. In fact, there really wasn't enough left of Pamela to call it a corpse. But she may not have been any more dead than Dave Churchill before the surgeons dismembered her.

As Dr. Sean O'Reilly, a Professor of Neurology at George Washington University told the BBC, "If a doctor or a committee declares a person to be dead before they are dead, they will be dead within a very short time if there is a rush to take organs."

In St. Louis, the BBC television crew talked to a girl named Polly Scott who had an unfortunate habit of taking drugs. One day she took too many, and an ambulance rushed her to the hospital where she was declared DOA -- dead on arrival. Like Dave Churchill, she was fully conscious through all of the tests, and she heard her doctors declare her brain dead. But her parents refused to accept the diagnosis, and they insisted that the doctors continue to treat their daughter's corpse.

Within days, Polly's corpse revived. As she talked to the BBC interviewer about her experience, she smoked a cigarette. Of course, we all know how unhealthy that is, but

Polly can probably be excused if she has less than total faith in medical science now. Polly was lucky that she had parents who could fight for her life.

There was a man named Ramirez who was not so lucky. When this 19-year-old Hispanic immigrant collapsed in front of a convenience store in Costa Mesa, California, on April 20, 1988, someone called an ambulance, and Mr. Ramirez was rushed to the Hoeg Medical Center, about 40 miles southeast of Los Angeles. Mr. Ramirez was not carrying any identification, much less an organ donor card. It happened that a doctor associated with that hospital had a heard disease and needed a heart transplant. The New York Times reported that even though Mr. Ramirez had drugs and alcohol in his system, he was declared brain dead. His heart was transplanted into the body of the doctor at the very time his parents were searching for their lost son. When they found him, he had no heart.

On September 20, 1989, the columnist, Mike MacElroy, of the New York Daily News wrote about a thriving traffic in the organs of crack victims who were brought to the Jacoby Hospital in the Bronx. He wrote: "The crack harvesting process is not illegal or even rare. It is a very important business finding clean hearts, kidneys, livers, and eyes." But the stories of Polly Scott and Dave Churchill are not uncommon either. One study concluded that as many as one in 12 of the people who are declared brain dead by various tests are really alive.

It is no surprise that we live in an age of nightmares; we live in an age of nuclear weapons, chemical warfare, destruction of the environment. We live with many, many nightmares, but from this nightmare there is no waking up. I believe it is up to the Committee here to protect the people of New Jersey from the nightmare of being declared dead when they are really alive. Otherwise, it could happen to any of us; too much to drink at the office New Year's party, a pill to help you sleep, a bad bump on the head and a trip to the hospital, and what next? May God save us from ourselves and from our doctors. But you can save us from this law by voting to kill A-1413 and S-1208.

Thank you.

ASSEMBLYWOMAN FORD: Thank you. Edward Daly?

EDWARD DALY: This won't be too long. As you can tell by looking at me, I am a senior citizen. I am a member of the American Association of Senior Citizens, Inc.

The AASC was in existence informally for a number of years before incorporating in New Jersey in 1988. Our networks in New Jersey and several other states are for the purpose of furthering the welfare of senior citizens. AASC networkers sponsor and participate in bioethics conferences, and have testified in several state legislatures on bioethical issues.

We are opposed to both of these bills. The members of our group are opposed to these bills because they may endanger the lives of senior citizens and other citizens of New Jersey if they are enacted into law.

The cost of medical care keeps rising at the same time the senior citizen population is increasing, while the population of employed taxpayers is decreasing. Medicare and Medicaid are one of the great expenses for State and Federal governments.

When these facts are considered altogether it is clear that government agencies have an interest in keeping down medical costs, and that measures taken to keep down costs inevitably have an important impact on senior citizens like myself. For this reason we find the provisions in Senate Bill No. 1208 and Assembly Bill No. 1413, which place the responsibility for the medical standards of brain death in the hands of the Department of Health and the Board of Medical Examiners, to be very dangerous. The State of New Jersey could gain financially if medical costs for senior citizens and certain comatose patients could be reduced by premature declarations of death and termination of life support. The medical standards for death should not be left to the Department of Health and the Board of Medical Examiners. Death is a permanent condition. It should be based on valid, scientific evidence, not on the decisions of bureaucracies.

Why do bills S-1208 and A-1413 not require that any standards set by the Department of Health and the Board of Medical Examiners be based on scientifically valid evidence? In a matter as important as the declaration of death of a patient, anything less than scientific validity in the medical standards that are used for brain death is unthinkable. The failure of S-1208 and A-1413 to require scientifically valid medical standards for declaring patients dead is made a thousand times worse by the provision in the bills to free doctors of criminal or civil liability or discipline for unprofessional conduct if they act in good faith.

Carpenters, painters, mechanics, dentists, and other professionals are not free from liability if they make a good faith effort. A carpenter has to build safe stairs; he can't make a good faith effort. A car mechanic, as Mr. Tomicki mentioned before, has to fix your brakes. He can't make a good faith effort. Why should a doctor be free to make a good faith effort and declare a comatose patient dead, and then be free of every type of liability, including civil and criminal?

Again I remind you that although S-1208 and A-1413 are dangerous, they are especially dangerous for us, senior citizens, in a climate of government cost containment.

In January of this year, a 79-year-old grandfather, Harold Sabolsky, of Ottawa, Canada, was declared to have been brain dead for 10 weeks. It was decided to disconnect his life support system. His family gathered around his bed to be there for his last moments. When the ventilator was disconnected, the gentleman's two-year old grandson called out from the doorway, "Grandpa." Grandpa sat up, extended his arms to his grandson, and just recently Mr. Sabolsky bought a new car and has been driving around Ottawa. I don't want to be another Mr. Sabolsky with these brain dead bills.

Rabbi Tannalow (phonetic spelling), who has written widely about medical ethics, has said: "A law that does not require doctors to use reliable methods to pronounce death is an immoral law." New Jersey is a State known for its concern for the weak and the vulnerable. We must retain these high standards by passing laws which provide adequate protections for our weakest members. Protection must be built into the laws themselves, and not left to bureaucracies. Bills S-1208 and A-1413 do not provide such protection, and we feel they should be rejected.

Thank you very much.

ASSEMBLYWOMAN FORD: Thank you, Mr. Daly.

Howard Nathan? I apologize, Mr. Nathan. I called you before, and I thought you weren't here.

HOWARD NATHAN: That's okay. Ira came up instead of me. Thanks very much. I'm sure you are very exhausted, as am I.

I am Howard Nathan. I am Executive Director of the Delaware Valley Transplant Program. We provide organ and tissue donation services for 26 hospitals in southern New Jersey. Our parallel organization is the New Jersey Network for Organ and Tissue Sharing.

I come here today to support Senate Bill No. 1208, with the exception of sections 5. and 6., as do the New Jersey Bar Association, the New Jersey Hospital Association, the New Jersey Medical Society, and the New Jersey Nurses Association.

My experience in the last 13 years has brought me face to face with about 1000 families who have been in this situation of having a brain dead loved one. I can tell you that what they are looking for is a specific diagnosis from the attending physician to declare that patient dead. Most of these people have not thought about this. It is not necessarily something that we all think about day to day at breakfast or dinner. But when they are faced with this situation, they depend upon the attending physician and the consultants to determine whether that person is alive or dead.

In those situations, perhaps the families may confuse emotional issues with religious beliefs. Obviously, when we lose a loved one, we are very emotional and we don't want to let go. As Dr. Ross testified, that is not an unusual response. But that should not be confused with-- A patient who is dead by brain criteria is no different than someone whose heart has stopped. There has been well documented literature, and you have heard much testimony about that.

I do want to share one other thing: In conjunction with the transplant issue, I am not here only as an advocate of organ transplant recipients -- and there are thousands waiting -- but for the families who may be in a situation where they get an opportunity to donate. Those families that I have talked to afterward are very thankful for the opportunity to save someone else's life, and we communicate that to them.

So, all in all, I want you to keep two things in mind: Death by brain criteria is the same as death by any other criteria. Death is death. This bill should not put the family in the position of having to make that determination for their loved one. It is a medical issue, and I think it really should be kept that way.

Thanks very much. Oh, one other issue: I want to leave with you case law in New Jersey called Strackon v. J.F.K., which you may be familiar with. It is a brain death situation that went to the Supreme Court of New Jersey, where brain death has been recognized by case law. It is a case from 1980. I will leave that with you.

ASSEMBLYWOMAN FORD: Thank you. Jeryl Maglio?

JERYL MAGLIO: I am a licensed nursing home administrator. I represent the Andover and Lincoln Park Nursing Centers, which is about 1400 beds in the State of New Jersey. We oppose S-1211 for many of the reasons you have heard.

To quickly outline some of them: Obviously, the withholding of food and water is euthanasia, and you have heard many of the issues with regard to that -- equal to active euthanasia. In fact, in Holland, where euthanasia is legal, citizens, particularly the elderly, look dubiously on the health care profession, and avoid, rather than seek medical attention. There, hundreds of thousands of patients die each year, not from their pathology, but from euthanasia.

One of the other reasons that we oppose the bill is because nonreligious affiliated institutions may not-- We cannot reject these new accepted medical practices and, in the case of Nancy Ellen Jobes, who happened to have been our patient, if that were to occur again, we could lose our license if we did not submit to the wishes of the family.

Also, under section 20b., we, as health care providers, would be required to educate our patients about living wills and to assist them in executing living wills. This violates our very moral, ethical, and religious conscience. In addition, we would be mandated to inform physicians, nurses, and other health care professionals of their rights and responsibilities under this Act, even if we do not agree with them. Really, the question is: Does the advance directive legislation supersede our constitutional rights of freedom of thought, freedom of speech, and freedom of religion?

Also, it would condemn certain groups of people to being nonentities with no rights, not even that of life. These people are declared, by designated individuals -- many of whom they have never known and would not choose themselves-- These designees can be two doctors who have no affiliation with the patient. They can be a relative not necessarily chosen by the patient. Once the patient is declared incompetent, this person can state what the patient would have wanted. And this evidence does not have to be beyond a shadow of a doubt. In fact, the New York Supreme Court differed with the New Jersey Supreme Court on cases with identical issues.

Of course, you have heard the criteria about terminal condition and sapient state. Of course, the terminal condition-- We disagree with that, too. With the terminal condition, the patient does not have to be in eminent danger of death. Many of our Alzheimer's patients, cancer, diabetes-- You have heard this before, so I won't belabor it. In fact, 40% of our 1400 patients would probably meet these criteria. If these patients could not eat, themselves, many who have to be spoon-fed would be subjected to death by starvation, if this legislation were enacted. They do not even have a living will. They need only be incompetent in order to lose the right to choose for themselves. If one does not think this is possible, there are many cases in the Ombudsman's Office in which the patient did not request that the feeding tube be removed; the family members did, and the patient was not even consulted. In the well publicized Hilda Peters case, the feeding tube was removed at the request of her boyfriend, and he is under investigation -- I don't know if the investigation has been completed -- for possibly poisoning her.

Regarding physicians' decisions differing, obviously in the Nancy Jobes case there were prominent physicians who did differ about her condition, who still, to this day are-- Two said she was in a vegatative state and two said that she was not. There were many shadows and doubts as to whether that was the right decision, and yet our criminals are afforded more protection.

And what about financial considerations? You have heard an awful lot about-- We are 90% Medicaid in our facility, and if living wills were in operation-- This is a statement that was made by a financial analyst of the Health Care Financing Administration. It came under a cost-saving initiative action. He said: "If living wills were in operation in all 50 states, the nation could save $1.2 billion."

There are a few other points, but I will just quickly say, patients' rights-- Patients already have a right to refuse treatment. However, we, as health care practitioners, are guided into thinking that we should assist patients in dying, instead of giving them care, because they are sick and will inevitably die. It is clearly discrimination. You have heard from the handicapped and the elderly, and we agree with their position.

In the case of attending physicians in our nursing homes, most of them only get a reimbursement of $7 a day. It is very, very difficult for doctors to visit the patients and adhere to even minimum requirements at $7 a day. These same physicians will be given the ultimate authority to decide who lives and who dies. In many cases, they don't even bother to see the patient, but take the wishes of the family.

What about if some of the recent New Jersey court decisions were changed, or were, well, overturned, as possibly happened in New York and California. They have taken dissenting views with the same cases. This demonstrates that even in circles where life and death issues are supposedly very clearly understood and deliberated, the controversies are diverse and the potential for abuse so great that we cannot afford to endanger the lives of our constituents, certainly not our nursing home patients, by subjecting them to this harm.

And, of course, you have heard that starvation is not painless. You have heard a lot about that. Statements we frequently share among the elderly, whether at home or in institutions, are: "I don't want to be a burden." ."I want to die in peace." These are very common. Many times we say them ourselves out of despair or loneliness, frustration, or even for attention. If statements like this were ever used, as has occurred in recent court decisions, as clear and convincing evidence when one is silenced by medical disability that one would desire death, we feel that certainly 80% to 90% of our patients in a nursing home would be in eminent danger of death with dignity, without the ability to defend themselves. And, in most cases that arise, the patient is not in eminent danger of death in which treatment is futile; that is, requesting to discontinue treatment. It is the case where the patient's only illness is old age, senility, they are there for ordinary comfort care, and no extraordinary measures are being asked to be discontinued. The patient, in most cases, is not even consulted.

In states where there are living wills, less than 20% of the population have them. What about the other 80%? Those who have such documents, in most cases, do not fully understand the implications, the misconceptions, the misnomers, such as terminally ill versus a terminal condition; irreversible illness, such as diabetes; the patient never returning to a cognizant sapien state -- and our senile elderly will never return to a cognizant sapien state -- and, of course, ordinary versus extraordinary. Well, now in our nursing homes, spoon-feeding a patient can be considered an extraordinary measure to take.

Beneath the rhetoric of the right to die legislation, what I think the bottom line question we are asked to evaluate is: Why should someone live if their life is worthless and has no meaning? In response, I believe to serve and care for another person, even if they are of no use to us, is an act of charity. I do believe that true human dignity does not lie in our freedom to choose, but in our desire to become more like our Creator, and our Creator teaches us: "Thou shalt not kill," and "Thou shalt love thy neighbor as thyself."

Just a few concluding statements comparing war and peace to the Universal Declaration of Human Rights, which was promulgated by the United Nations and was the result after the Second World War. A few statements made by the Pope on his tour to America-- One of the things was: "The Universal Declaration of Human Rights is the fundamental document of all human beings. Every human being, according to this Universal Declaration is endowed with dignity that must never be lessened, impaired, or destroyed, but must be respected and safeguarded if peace is to be built up."

It goes on to say that the most important of human rights that are universally recognized are those of life, of liberty, of security, and the personal rights to food, clothing, and having sufficient health care; also our freedom of conscience and of religion. These, all taken together are in keeping with the substance of the dignity of the human being. Nowhere does it mention a right to die. It goes on to say: "The spirit of war springs in its basic meaning and grows to maturity when the inalienable rights of man are violated."

In the Second World War, the injustice that was violated was that against the handicapped whose quality of life had no value, and inevitably soon to follow, the social order was destroyed, and then everyone knows what followed that. Any violation of human rights, even in peace, is a form of warfare against humanity.

In modern civilization, sensitivity to the spiritual dimension of human existence is diminished as a result of certain premises which reduce the meaning of human life to chiefly material and economic factors. This cannot be more evident than right here in New Jersey -- the living will legislation which reduces the value of life to meaninglessness for the purpose of ending it.

ASSEMBLYWOMAN FORD: Ms. Maglio, may I just ask you to summarize? You have been testifying for 15 minutes. My list has two more people, and I have to end the hearing at 5:00. So, in deference to them--

MS. MAGLIO: Okay. Well, I think that pretty much would summarize basically what we would like to say.

ASSEMBLYWOMAN FORD: Thank you. Theresa Gleason?

THERESA GLEASON, R.N.: Thank you, Chairwoman Ford and members of the Committee -- the ones who are left who stuck it out -- for the opportunity to testify in behalf of our organization, the National Nurses for Ethical Concerns. This represents at least 400 nurses in New Jersey and across the United States, including nurses who are outside of the country. It has affiliation with New Jersey Right to Life Nurses, National Right to Life Nurses, the International Catholic Nurses Association, and other organizations.

I would like to say that because of my opposition to these bills, I hope to inform these groups, through anything I can do, to muster up a continual challenge to defend life.

We would like to comment on the Declaration of Death Act -- S-1208 and A-1413. If you were to look in the medical literature for the various criteria for brain death-- This should help you to put your teeth into some scientific background. If you examine the Harvard criteria, the President's Commission's criteria, the Minnesota criteria, in fact all of the criteria, you will note that the first requirement is that the patient be in a coma.

At the beginning of August 1968, the Ad Hoc Committee of the Harvard Medical School first declared that certain comatose people should be considered dead. This was done one year after Dr. Christian Barnard performed the first heart transplant. The Harvard Committee gave no scientific proof for translating coma into death. It was not science, but rather it was an edict. Calling a comatose person dead is a contradiction. Only a living person can be in a coma.

Furthermore, we would like to point out the weakness of the criteria that are being used for brain death. In the interest of brevity, my remarks will be confined only to one aspect of the brain death criteria -- the EEG, the electroencephalogram. In the EEG, electrodes are attached to the scalp in order to detect the electrical activity of the cortex, the outermost portion of the cerebrum. The EEG tests only a few millimeters below the scalp. When an EEG is given to a patient who is being considered for brain death, the patient is usually in the intensive care unit and, as you have heard, heart monitors, ventilators, and other items in the room may produce artifacts in the EEG tracing.

When a patient has electrical activity on the brain but the activity is low, it can be masked by the noise that is created by other machines in the ICU, the nurses' movements, etc. Bickford and his coworkers tested the ability of electroencephalographers to interpret the EEG. Records of low brain activity were used. Types of "R" waves from an electrocardiogram were then superimposed upon the low EEG records. Bickford found that fully trained electroencephalographers -- the technicians -- were unable to recognize reliably EEG slow wave activity; that is, less than 25% of the amplitude of the electrocardiogram appearing on the record. In other words, a record may appear to be a flat EEG, when actually slow brain activity has been hidden by interference from other ICU machines.

It should be remembered that the electroencephalographers tested by Bickford were fully trained. The largest study of brain death is the collaborative study of the NIH -- the National Institutes of Health. Fully trained electroencephalographers gave their opinions as to whether or not the patient had a flat EEG. Then, a panel of senior EEG consultants reviewed 303 of the EEGs. The opinions of the consultants differed from the opinions of the electroencephalographers in 13% of the cases.

Since experts have such a high level of disagreement, and since electroencephalographers often cannot recognize slow activity when the record is contaminated by noise from the ECG -- the electrocardiogram, it seems less than ethical that EEG evidence is being used to declare comatose patients dead.

Furthermore, a flat EEG does not mean that the situation is irreversible. Drugs, cold, shock, trauma, various diseases can cause a loss of brain activity which is reversible. People have had EEG activity return after weeks or months with a flat EEG. Jorgensen showed return of EEG after eight hours of a person meeting the clinical criteria for brain dead. The EEG detects activity only a few millimeters below the scalp. Researchers have reported that patients with flat EEGs may sometimes have brain activity deeper inside the brain. Such activity in the inner part of the brain has been reported by several researchers -- Carbinel, Phizer, Binchu (names spelled phonetically), for example. The EEG is quite complicated and is difficult to give properly.

As of August 1, 1984, only 1433 individuals have been certified by the American Board of Registration for EEG technologies. Also, to interpret the EEG properly is very difficult and requires highly trained clinical neurophysiologists. By the end of 1984, the number of physicians certified by the American Board of Qualification in Electroencephalography was at that time only 533. These statistics indicate that in the United States, with its population of millions, there is a good possibility that the person testing a comatose patient to determine his brain activity may not be adequately qualified.

There are many weaknesses in the EEG in the determination of brain death. What we have just said about the EEG can also be said about other tests of the brain, including the clinical tests and the blood flow tests. We will be very glad to send you articles from medical literature to verify the statements made in this testimony.

ASSEMBLYWOMAN FORD: Thank you.

ASSEMBLYMAN NAPLES: Thank you.

ASSEMBLYWOMAN FORD: Kim Citro? (no response) That is all the names I had, and I want to thank those of you who stayed throughout this hearing.

Assemblyman Naples, do you have any further comments for the record?

ASSEMBLYMAN NAPLES: Very quickly I just want to say-- I want to commend you, first, for doing a beautiful job. I know what it is like to conduct a hearing. (applause) Thank you, too, for the honor of allowing me to sit here. I know what it is like to Chair -- I am the Chairman of the Assembly Education Committee -- an eight-hour hearing. It's really tough being fair to all points of view.

I heard a lot of emotion, wholesome emotion. There is a difference between emotion and irrationality based on commitment. People know where I stand, obviously, being the sponsor of A-16. But I learned a lot, and I respect every point of view.

Lastly, I just want to say that Lisa Randall -- Assemblywoman Randall -- the co-sponsor of Assembly Bill No. 16, from Bergen County, was going to be here -- she called me -- but she had to be in court.

Thank you very much again, Marlene.

ASSEMBLYWOMAN FORD: Okay, thank you. That will conclude the public hearing on this package of bills. We will put out, obviously, a public notice when we are going to hold a hearing on whether or not to release the bills from Committee, and what shape and form those bills will take. But I am sure that the Committee members will be interested at this point in reviewing some of the testimony that was presented -- some of the written testimony. As you can see, I have about six inches high of new documentation to read on this. So I thank you for your--

MR. TOMICKI: (speaking from audience) Madam Chairman, may I ask if you will allow me to put something else on the record? (no response)

One of the things that we forgot to do today, trying to accommodate the Committee on time-- We have testimony from a Dr. Paul Byrne, who is an expert in this field. We would like the opportunity, on behalf of New Jersey Right to Life, to submit that, along with an article on brain death criteria, for incorporation in the record.

ASSEMBLYWOMAN FORD: Okay, no problem.

MR. TOMICKI: We will deliver that to the Committee.

Would it be the Chairman's position that you will wait for the transcript to be done before the Committee will--

ASSEMBLYWOMAN FORD: I don't know when the transcript will be done. I don't know how backed up they are. I would anticipate trying before the end of the year to schedule another hearing on this, but right now my schedule is also up in the air because of the Speaker changing the Committee meeting date. So I am not quite sure when the Judiciary Committee will be regularly scheduled to meet again. But as you know, you will get plenty of notification on it.

MR. TOMICKI: We thank the Chairman.

ASSEMBLYWOMAN FORD: Thank you. That concludes the hearing.

(HEARING CONCLUDED)

APPENDIX

New Jersey Catholic Conference

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Most Rev. Theodore E. McCarrick
Archbishop of Newark
President

William F. Bolan, Jr., Esq.
Executive Director

STATEMENT
OF
NEW JERSEY CATHOLIC CONFERENCE
IN CONNECTION WITH PUBLIC HEARING
OF
ASSEMBLY JUDICIARY COMMITTEE REGARDING
S-1208, S-1211 ET AL.

November 15, 1990

This memorandum is submitted to the Assembly Judiciary Committee for the purpose of informing the committee of the position of the New Jersey Catholic Conference with respect to eleven bills dealing with advance directives, medical powers of attorney and declaration of death which are the subject of this public hearing.

We first address the New Jersey Declaration of Death Act (S-1208), see also A-1413. By the terms of S-1208, an individual whose circulatory and respiratory functions can be maintained solely by artificial means, and who has sustained irreversible cessation of all functions of the entire brain, including the brain stem, shall be declared dead. The Catholic Conference supports this bill because it sets the standard for declaration of death as total brain death. The bill recognizes that the actual determination of death is to be limited to those situations where all activity of the brain has ceased, including that of the brain stem. We believe it is more properly within the province of the Legislature and not the courts to set such a standard. We regard this measure as a protection for human life because it sets a standard which prevents a premature determination of any person's death. This bill draws the line at life's end where it should be drawn, not at some point earlier when health or consciousness is fading.

We next turn to the "New Jersey Advance Directives for Health Care Act," S-1211 (A-16 and A-2514 are identical bills). In addressing S-1211, we think it important to note that an earlier version of the Declaration of Death bill (now S-1208), was amended to accommodate the beliefs of certain religious persuasions (see sections 5 and 6 of S-1208). We submit that similar considerations ought to be given to the beliefs of other groups who find that S-1211 and similar legislation raises significant moral problems.

The New Jersey Catholic Conference recognizes that substantial efforts have been made by the New Jersey Bioethics Commission to grapple with the issues surrounding an advance directives act. We have expressed our gratitude to the Commission for the time and effort which it has contributed to this endeavor. Nevertheless, some of the provisions of this proposal raise significant moral problems, highlighting the need for serious debate on the purpose and risks of legislation on this subject. The Catholic Bishops feel a responsibility to contribute to this debate. They are concerned that legislation which is ethically unsound will further compromise the right to life and respect for life in our society.

Those provisions of the proposed act which we will discuss in this statement are so fundamentally inconsistent with our moral tradition that if they remain in their present form they will intrude on the religious and moral beliefs of a substantial majority of the citizens of this state. The deprivation of life-sustaining treatment or fluids and nutrition to patients who are not terminally ill, and the absence of a section dealing with the provision of these life-sustaining measures to a pregnant woman, are the most notable examples of the deficiencies of this act in our judgment. Firmly embedded in our moral tradition is the principle that it is possible to kill innocent persons by acts of omission, as well as acts of commission. Whenever the failure to provide appropriate medical treatment or adequate food and fluids carries out a proposal, adopted by choice, to end life, such an action is an act of killing by omission. In short, it is passive euthanasia. We absolutely reject euthanasia, by which we mean any affirmative or deliberate act or any deliberate omission intended to end life rather than to permit the natural process of dying.

The most critical provisions of the act involve those dealing with the decisions to forego life-sustaining treatment and artificially provided fluids and nutrition. We first address certain fundamental principles. Every person has the duty to preserve his life, care for his own health, and seek necessary medical care from others, but these principles do not mean that all possible remedies must be used in all circumstances. One is not obliged to use "extraordinary" means; that is, means which offer no reasonable hope of benefit or which involve excessive hardship. Such decisions are complex and should be made by the patient in consultation with his or her family and physician whenever possible. Obviously, the easiest case is presented by a patient who is conscious and competent and has had the opportunity of full consultation with the medical staff and the family.

The worst scenario would be to create an advance directives statute which might make the law a partner, by virtue of an automatic triggering of an advance directive:

a. in creating a life-threatening situation actually opposed to the best interests of a non-dying, unconscious or incompetent patient, or

b. in substituting a decision of the remote past, possibly not geared to the medical and personal realities of the present.

What can readily apply to the truly terminally ill does not, and should not, apply to non-dying patients, even those who are comatose or unconscious.

In discussions of this matter, a basic point that must be kept in mind is that for non-dying patients the discontinuance of fluids and nutrition does not simply allow the person to die from existing pathology, but it initiates a new cause of death -- starvation or dehydration. Too often, lurking behind the decision to withdraw fluids and nutrition is the assumption that the quality of life has so deteriorated that the patient would be better off dead. Such thinking opens the door to euthanasia. Human life, however, is a basic good and the foundation of other goods, notably personal dignity and human rights. All reasonable efforts should be made to sustain life, and thus there should be a presumption in favor of providing fluids and nutrition to the unconscious, non-dying patient unless or until the benefits of fluids and nutrition are clearly outweighed by a definite danger or burden to the patient, or are totally useless. Of and by itself, coma, permanent or not, does not justify direct termination of the patient's life. It must be emphasized that the judgment made here is not that the person's life is useless or excessively burdensome; rather, the judgment made is that the means used to preserve life is useless or excessively burdensome.

Thus, our position is that the withdrawal or withholding of life-sustaining treatment or the artificial provision of fluids and nutrition should be limited to terminal cases arising from irreversible pathology from which death is imminent. Terminal illness would be defined as an incurable or irreversible condition that, according to the best available medical judgment, will result in imminent death from an irreversible pathology.

Turning to the specific language of this bill, we offer a number of amendments which are attached to this statement. The following is a commentary on those amendments.

In section 2 on page 1 of the bill, we have deleted "fundamental" as the modifier of "right" because the term "fundamental" is ambiguous. Is it a natural right? Is it a constitutional right? How and in what sense is it a fundamental right?

In subsection b, the bill makes clear that the State recognizes the inherent dignity and value of human life and within that context recognizes a right to make health care decisions. We also clarify that decisions to have life-prolonging medical or surgical means or procedures provided, withheld or withdrawn should be done "when they are perceived by a patient as hopeless or unduly burdensome."

In the legislative findings we have added a sentence which makes clear that any doubts which arise concerning the applicability of any of the interventions set forth in this act shall be resolved on the side of preserving life. This formulation was drawn from A-776, sponsored by Assemblyman Karl Weidel, an original member of the Bioethics Commission, and a number of other legislators in the 1986 session.

In subsection e on page 2, we have deleted a reference to active euthanasia. We maintain that there should be no distinction between active and passive euthanasia. There should be no doubt, for example, that assisted suicide or omissions creating a threat to life not otherwise at risk would clearly constitute euthanasia.

On page 3 we have added a definition of euthanasia, the absence of which was a serious deficiency. Euthanasia means any affirmative or deliberate act or any deliberate omission intended to end life rather than to permit the natural process of dying. This formulation was drawn from section 11 of the Florida law (Life-Prolonging Procedure Act). See West's F.S.A. §765.11

On page 3, we have deleted the second definition of health care decision which includes a decision to accept or refuse the services of a particular health care professional and a decision to accept or refuse a transfer of care. First, what is spoken of here is not, in fact, a health care decision. Secondly, we believe it is unacceptable to compel an institution to violate its conscience, in a case where a patient would refuse a transfer but would insist upon action which violated the conscience of the institution. We think the approach which would adequately and completely protect the institution's conscience and the patient would be to permit the transfer of a patient in that case.

On page 3, we have deleted the requirement that the use of life-sustaining treatment must increase the expected life span of a patient. It is unclear whether life span is intended to be life span in accordance with statistical tables or life span in accordance with the particular pathology of this patient. Is it not sufficient for the life-sustaining procedure to stabilize the patient? To impose the condition that life-sustaining treatment must increase the expected life span of a patient is unreasonable.

We note that under the definition of "health care representative" on page 3 that a non-family member can be so designated, even if this designation would cut off a spouse or children. While we do not insist upon a change here, we do observe that this tends to undermine the integrity of the family.

We have deleted completely the definition of "permanently unconscious" on page 4 of the act. There is no medical definition of "consciousness." See Stedman's Medical Dictionary 1710 (21st ed. 1966). It is not a medical term because by its nature it cannot be tested empirically. An assumption is being made here that one can have medical certainty about another human being's internal mental states.

The definition of "terminal condition" is defective in our judgment. The definition should not say what it is not, or should not be based on preconditions or periods of time. We propose the following: "Terminal illness means an incurable or irreversible condition that, according to the best available medical judgment, will result in imminent death from an irreversible pathology."

We have deleted reference to video or audio tape recording as unnecessary in legislation since there exists no impediment to doing so.

On page 4 we have deleted the automatic revocation of the declarant's spouse upon divorce or legal separation on the theory that a declarant should be able to decide this issue.

On page 5 we have amended subsection 5 to require that the declarant shall state the authority of the health care representative in addition to the limitations required by the proposed act. We believe that it is important in a document of this magnitude that specific authority should be set forth even if in general terms.

Under section 6b a declarant may instruct that artificially provided fluids and nutrition shall be withheld or withdrawn under certain conditions by so indicating through an explicit statement in the instruction directive. We have added a provision that the withholding or withdrawing of artificially provided fluids and nutrition shall not be permitted if such action, rather than the underlying terminal illness or injury, would be the sole or principal cause of the patient's death.

Pursuant to section 8, if an attending physician determines that a patient lacks decision-making capacity, his determination shall be confirmed by one or more physicians. The section continues that confirmation of a lack of decision-making capacity is not required when the lack of decision-making capacity is clearly apparent and the attending physician and the health care representative agree that confirmation is unnecessary. We have deleted that paragraph. We see no good reason for obviating confirmation by another physician, which is commonplace in many areas of modern medicine. That provision could be a shield for the negligence of the attending physician.

In subsection g of section 8, it provides that a determination that a patient lacks decision-making capacity shall be based upon an evaluation of the patient's ability to understand and appreciate the nature and consequences of a particular health care decision, including the benefits and risks of an alternative to the proposed health care and to reach an informed decision. We believe that that standard is so high that no one but another physician could attain it. Obviously, a health care decision can be much more basic than the standard portrayed in subsection g. Accordingly, we urge that it be deleted.

Subsection b of section 9 on page 7, provides that the health care representative shall retain his authority even if a patient has a legal guardian, "unless the terms of the legal guardians's court appointment ... provide otherwise." It is the patient's wishes, not a court's, that ought to control. Accordingly, we delete the last phrase.

Under section 11 on page 9, if a patient who lacks decision-making capacity clearly expresses or manifests the contemporaneous wish that medically appropriate life-sustaining or artificially provided fluids and nutrition necessary to sustain life be provided, that wish shall take precedence over any contrary decision of the health care representative and any contrary statement of the patient's instruction directive. We support that provision, for it is a clear signal to the health care representative and health care professional that they must abide by the known wishes of the patient that life-sustaining treatment be provided.

We have amended subsection d. to provide that an instructive directive shall be inoperable if it does not provide clear direction as applied to the patient's medical condition and treatment alternatives.

On page 10, we have deleted the provision which validates instruction directives executed prior to the effective date of this act. Since they would not have the same safeguards that are present in this act they would be deficient and thus should not be validated.

In section 13 on page 10, a health care institution is required to adopt policies and practices to provide appropriate informational materials concerning advanced directives to all patients and their families and health care representatives. We have deleted this provision for we do not believe that a health care institution should be burdened by statute with being a missionary for advance directives. If they wish to engage in this educational process, they ought to be free to do so and not be compelled by statute.

We enthusiastically support the provision in section 10 which protects the professional conscience and the provision in section 13 which protects the conscience of religiously-affiliated health care institutions. Our amendment would delete "religiously-affiliated" so that that provision would apply to all private health care institutions. The failure to include all institutions ignores the fact that the moral values (e.g., Hippocratic oath, respect for life) on which professional conscience is based also may shape the institutional conscience. We submit there is ample legal authority for applying institutional conscience to non-religiously affiliated hospitals. The Bioethics Commission's proposed legislation on determination of death recognizes not only a religious exemption but also one grounded in personal moral convictions. See Senate Bill No. 1208. Our Supreme Court in Jobes left open the possibility that an institution's policy not to participate in the withdrawal or withholding of artificial feeding, if communicated in advance to the patient, would be upheld. Throughout the act is the notion that patient choice is paramount. What is neglected is the equally viable principle that a hospital or a health care institution should not be compelled to violate its moral and ethical principles. If a private non-religiously affiliated health care institution notifies a patient that its policy prohibits the withdrawal or withholding of life-sustaining treatment and artificially provided fluids and nutrition, such a policy should be honored so that the institution can be faithful to its code of ethics.

In section 15, we have deleted the section which permits life-sustaining treatment to be withheld or withdrawn from a patient who is permanently unconscious. Our rationale is contained in our previous comments regarding the definition of "permanently unconscious." Subsection 3 of section 15 regarding terminal condition is acceptable provided that our amendment regarding the definition of terminal condition is accepted.

In sections 15 and 16, we have deleted that provision which provides that nothing in the section shall be construed to abridge any constitutionally protected right to refuse treatment based on the free exercise of religion or the right of privacy under the constitutions of the United States or the State of New Jersey. If a state or federal court decides to overrule this legislation as unconstitutional, it has the power to do so regardless of this statement. It would be hoped that the courts would pay substantial deference to the judgment of this Legislature as reflective of the will of the people.

We have amended section 16 to provide that the burden spoken of should be referable to the intervention itself and not to the quality of the continued life of the patient. We have also added to that section the provision that notwithstanding the other provisions of this section the withholding or withdrawal of artificially provided fluids and nutrition shall not be permitted if such action, rather than the underlying terminal illness or injury, would be the sole or principal cause of the patient's death.

Section 26 provides that the withholding or withdrawing of life-sustaining treatment or artificially provided fluids and nutrition shall not constitute homicide, suicide or active euthanasia. We find that provision acceptable only if our amendments to the sections on life-sustaining treatment, artificially provided fluids and nutrition and deletions of the definition of permanently unconscious and the definition of terminal illness are accepted.

In section 26 we delete the provision regarding durable powers of attorneys. We have objections to durable powers of attorney for health care executed pursuant to N.J.S.A. 46:2B-8. The power of attorney vests the attorney in fact with unlimited powers. Such powers are not surrounded by the safeguards that this act attempts to provide and which we, in our judgment, have fortified by our amendments. We fear that if a third party can be given absolute power to omit even ordinary means in order to hasten a patient's death, this can be a spring board to invalidating laws against assisting suicide. If the legal distinction between the patient and attorney in fact can be obliterated so that the attorney in fact has all the power that the patient would have had over himself, we see this as a step along the road to legitimizing euthanasia.

A glaring deficiency in the act is a lack of statutory protection for the unborn child of a pregnant woman who may be subject to the withdrawal or withholding of life-sustaining treatment or artificially supplied fluids or nutrition. The

Life-prolonging Procedure Act of Florida expressly states that an advance directive shall have "no effect during the course of a pregnancy." See West's F.S.A. §765.08. We recommend the same language for this act. The absence of such a provision is not required by any of the United State Supreme Court decisions which removed most of the restrictions on abortion.

The issue before us is not the unfettered right to control one's medical care but rather the exercise of that right within ethical limits. Based upon our review of the advance directives act, we fear that the Bioethics Commission is attempting to create a theology or morality by consensus which is doomed to fail. Life-sustaining treatment, as well as fluids and nutrition, are necessary for the preservation of life. Law and morality should recognize a strong presumption in favor of them. Decisions to forego these means of upholding life should be examined carefully to be certain that such determinations are not guided by a discriminatory attitude regarding the value of the lives of persons with disabilities or by an intention of deliberately hastening the death of such persons. We must insure that these judgments are not made in the name of cost containment or transplant urgency.

We next consider the remaining bills which are not products of the Bioethics Commission's efforts but relate to the same or similar issues. These bills take several approaches and we will address each one separately. We will not repeat what we have said before where a bill repeats a concept but instead will address the different features presented by these other bills.

A-2466 is known as the "Medical Power of Attorney and Treatment Decision Act." This bill authorizes either a written directive instructing a physician to withhold or to withdraw life-sustaining procedures in the event of a terminal condition, as well as the right to make a written directive reaffirming that life-sustaining procedures should be continued or initiated. The bill also recognizes a written medical power of attorney directive. In the latter document, an individual appoints an agent who in the event of the incapacity of the individual will have the authority to decide to withhold, withdraw, continue or begin life-sustaining procedures. The bill further provides that the provision of food and fluids shall be continued unless the attending physician has made a specific determination that the continuation would be medically inappropriate. We think that this provision is vague since there is no definition of the term "medically inappropriate." We believe that there should be a presumption in favor of providing fluids and nutrition to the unconscious, non-dying patient unless or until the benefits of fluids and nutrition are clearly outweighed by a definite danger or burden to the patient, or are totally useless.

The bill defines terminal condition as "incurable or irreversible condition or combination of conditions that will result within a relatively short time in death." The use of the term "relatively short time" introduces an undesirable and expansive ambiguity into the entire concept of terminal illness. By ignoring or even rejecting any accepted medical or other objective standard, the bill would invite a comparison and a value judgment concerning the shortness of time left to a dying patient. The legitimacy of withholding treatment from a patient must not and cannot turn on any artificial calculation that depends on time alone but can only be allowed to turn on the progress of a patient's terminal condition. The use of the expression "relatively short time" would constitute legislative permission to withhold medical treatment prior to the last stages of an illness. This permission would fall within the classic definition of euthanasia, a deliberate act or omission by which a person intends to cause the death of another. We note with approval the presence of a pregnancy exception. See sections 6a.

A general observation regarding powers of attorney is in order. Powers of attorney tend to be more permanent instruments with a separate dignity of their own and can exist unnoticed for many years. People's attitudes and predilections may change in these periods. There should be some thought of a time limitation on the effect of such a document or, failing that, at least a periodic renewal requirement. Powers of attorney are popular documents used for the practical administration of physical assets in the event of disability. A person's attitudes toward assets does not change but their attitudes toward medical care may change based upon state of the art medical procedures and person's responsibility that undergo constant change due to marital status, the age of children and their dependency of others. A-2467, (which is a companion bill to A-2466) deals with a situation where a person has not executed a directive to a physician or a medical power of attorney. When a person has not executed a directive to a physician or a medical power of attorney, a surrogate decision maker who believes that the incompetent patient would have wanted treatment withdrawn or withheld may bring the matter to the attention of the attending physician. Under the bill a hierarchy of individuals who may act as a surrogate decision maker is created and is headed by the patient's spouse. It must be emphasized that this bill goes farther than any of the other legislation in that it applies to decision making for incompetent patients who have not previously executed an advance directive. The New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care did not address this observing that "the Commission has not yet fully considered a number of issues relating to decision making for incompetent patients without advance directives, including the circumstances in which life-sustaining provisions may be withheld or withdrawn from such patients and the respective roles of family members, physicians, ethics committees and state agencies in making such decisions. See "Problems and Approaches in Health Care Decision Making: The New Jersey Experience," page 44. We would suggest that given the lack of study of this very critical question that consideration of A-2467 at this time is premature.

A-2492, known as "New Jersey Health Care Directive Act," provides either a treatment directive or a medical decision power of attorney dealing with an individual's ability to determine whether or not to receive health care and to have specific treatment or procedures initiated, withheld or withdrawn. It is similar A-2466. A-1191 is known as the "Death with Dignity Act." It authorizes an adult to execute a declaration directing the withholding or withdrawal of life-sustaining procedures when the individual is in a terminal condition. The principal defect in this measure is the absence of a definition of a terminal condition.

A-1341 is known as the "Right to Die Act." The title of the bill itself has come to be a slogan which advances the agenda of those who would legalize euthanasia. This bill truly is a right to die bill since its operative provision provides "a person eighteen years or older may execute a right to die document directing that if the person is ever certified to be suffering from a terminal illness, life-sustaining medical treatment shall not be administered to prolong that person's life." To see how close this bill comes to the authorization of euthanasia, one need only look to the definition of terminal illness. It is defined as "an incurable condition caused by injury, disease or illness which, within reasonable medical judgment, will ultimately produce death and the application of life-sustaining procedures serve only to postpone the moment of death." There are many diseases which will produce death ultimately but death may not occur for twenty or thirty years after the onset of that disease. For example, certain cases of diabetes may be classified as terminal but with appropriate use of insulin the moment of death may be postponed for many, many years. Under the definition of terminal illness in this bill, a person could be allowed to die at the early stage of diabetes.

A-2957 is known as the "Natural Death Act." Again, this bill provides for the execution of a directive directing the withholding or withdrawal of life-sustaining procedures in the event of a terminal condition. Terminal condition is defined in the same fashion as the preceding bill and thus is equally objectionable to us.

In conclusion, we must be vigilant because there is a segment in our society who is not only not reticent but also is eager to hasten the death of terminally ill patients. Indeed, as reported in the New England Journal of Medicine of March 30, 1989, a majority of a group of doctors at a meeting held under the auspices of the Society for the Right to Die in Boston in 1987, stated their belief that it is not immoral for a physician to assist in the rational suicide of a terminally ill person. The article speaks of a physician prescribing sleeping pills with knowledge of the patient's intended use for suicide or by discussing the required doses and methods of administration with the patient.

We urge you to resolve the questions presented here in favor of preserving life. After all, these are matters of life and death for some of the most helpless members of our society. Above all, public policy in this area must be based on a positive attitude toward disabled and terminally ill patients, who have a right to live with dignity and with reasonable care until the moment of natural death. In sum, we urge you to support S-1208 but to not support S-1211, or any other bill listed here today unless the bill is amended in accordance with the proposals made in this memorandum.

Elmer M. Matthews, Counsel
New Jersey Catholic Conference

N.J.C.C.
Requested
Amendments

Assembly Judiciary Committee Amendments

to

Senate Bill No. S-1211

Amend:

Page	Sec.	Line	
1	2	9	Omit "fundamental"
		25	Omit "fundamental"
		27	Omit "." Insert ", when they are perceived by the patient as hopeless or unduly burdensome."
1	2	42	After "value." Insert "Thus, any doubts which arise concerning the applicability of any of the interventions set forth in this act shall be resolved on the side of preserving life."
2		18	Omit "active"
		20	Omit "active"
3	3	after 8	Insert a new section as follows: ""Euthanasia" means any affirmative or deliberate act or deliberate omission intended to end life rather than to permit the natural process of dying."
		12	Omit ""health care decision" also means a"
		13-16	Omit
		44	Omit ", and thereby increase the"
		45	Omit "expected lifespan of a patient"
4	3	2-8	Omit
		17-23	Omit Insert a new section as follows: ""Terminal condition" means an incurable or irreversible condition that, according to the best available medical judgment, will result in imminent death from an irreversible pathology."
	4	30	Omit "An"
		31-32	Omit
4	5	47-48	Omit
5	5	1	Omit
		2	Omit "d." Insert "c."
		10	Omit "e." Insert d."
	6	44	After "state", Insert "specifically the authority of the health care representative and"
		44	Omit ", if any,"

_____________ Amendments

to

Senate Bill No. S-1211

Amend:

Page	Sec.	Line	
5	6	46	After "b." Insert "if"
		46	Omit "may"
		46	Omit "execute" Insert "executes"
		47	Omit "the"
		48	Omit "declarant's general treatment philosophy and objectives; or"
6		2	Omit "of any form of health care, including"
		3	Omit "; or both. An instruction directive may," Insert "."
		4-5	Omit
	6	9	After "directive." Insert "The withholding or withdrawing of artifically provided fluids and nutrition should not be permitted if such action, rather than the underlying terminal illness or injury, would be the sole or principal cause of the patient's death."
	8	30-33	Omit
		43	Omit "the" Insert "any"
7		2	Omit "he" Insert "the patient"
		3	After "capacity," Insert "shall inform the patient's family"
		10	After "patient" Insert ", the patient's family"
		13	After "implementing" Insert "the specific instructions of"
		17-22	Omit
	9	30	After "retain", Omit "legal"
		31	Omit "," Insert "."
		32-33	Omit
		34	Omit "legal"
		41	Omit "exercise" Insert "have"
		43	Omit ", and" Insert "in order"
8	11	47	After "discuss" Insert "with the patient"

____________ Amendments

to

Senate Bill No. S-1211

Amend:

Page	Sec.	Line	
10	11	5	After "the", Insert "instruction directive shall be inoperable."
	11	6-12	Omit
	12	14	After "if" Omit "n"
		16	Omit "able" Insert "unable"
		16	Omit "available" Insert "unavailable"
		26	Omit "a legally appointed guardian, if any,"
		26	Omit "or"
		27	After "behalf" Insert "or a legally appointed guardian, if any,"
		35-37	Omit
	13	46-48	Omit
11	13	1-3	Omit
	(3)-(6)	4-30	Renumber as subsections "(2)" through "(5)"
		19	After "shall" Omit ","
		19	Omit "take all"
		20	Omit "reasonable steps to effect" Insert "cooperate in"
		36	Omit ", religiously affiliated"
12	15	29	Omit "Consistent with" Insert "As required by"
		38-40	Omit
		41	Omit "3" Insert "2"
		44	Omit "4" Insert "3"
		44	Omit "none" Insert "neither"
13	15	13-17	Omit
	16	18	Omit "Consistent with" Insert "As required by"
		24	After ";" Insert "or"
		25-27	Omit
	15	28	Omit "3" Insert "2"

_____________ Amendments

to

Senate Bill No. S-1211

Amend:

Page	Sec.	Line	
13	15	34	After "inhumane" Insert ", provided that the determination of burden shall refer to the intervention itself and not to the quality of the continued life of the patient"
14	16	4-8	Omit
		after 8	Insert a new section as follows: "d. Notwithstanding any other provision of this section the withholding or withdrawing of artificially provided fluids and nutrition shall not be permitted if such action, rather than the underlying terminal illness or injury, would be the sole or principal cause of the patient's death."
15	20	40-43	Omit
		44	Omit "Educate" Insert "Inform"
17	25	4	Omit "or the State of"
		5	Omit "New Jersey" Insert "and of this act"
		7	Omit "or the State of New Jersey" Insert "and of this act"
		7	Omit ", and not"
		8	Omit "contrary to the public policy of this State,"
	26	22-25	Omit
		after 27	Insert new subsection as follows: "d. An advance directive shall have no effect during the course of a pregnancy."

State of New Jersey

Commission on Legal and Ethical Problems in the Delivery of Health Care
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CHAIRMAN

SISTER JANE FRANCES BRADY
ICE-CHAIRMAN

ROBERT S. OLICK, ESQ.
EXECUTIVE DIRECTOR

November 15, 1990

The Honorable Marlene Lynch Ford, Chair
Judiciary, Law and Public Safety Committee
New Jersey General Assembly
State House Annex
Trenton, NJ 08625

By Hand

Dear Assemblywoman Ford:

We would like at the outset to thank you for the opportunity of addressing the Committee today. Its important deliberations on the Advance Directives for Health Care Act and the Declaration of Death Act are central concerns to the overwhelming majority of New Jersey citizens. In addition to our oral testimony, please find enclosed the following documents:

1. Written testimony on behalf of the Bioethics Commission;

2. Position papers on the New Jersey Advance Directives for Health Care Act and the New Jersey Declaration of Death Act, with attached lists of supporters;

3. Advance directives for health care forms and informational/educational materials;

4. A pamphlet entitled "Understanding Brain Death"; and

5. Recent supportive editorial and news publications.

On behalf of all 27 Commissioners, we thank you again for your continuing support of the Commission's ongoing labors and we, the Commission's Executive Director, Robert Olick, and professional staff, stand ready to assist as the bill proceeds through the legislative process.

Sincerely,

Paul W. Armstrong, Esq.
Chairman

Sr. Jane Frances Brady
Vice-Chairman

cc: Patricia K. Nagle

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EXECUTIVE DIRECTOR

PUBLIC HEARING TESTIMONY

THE ADVANCE DIRECTIVES FOR HEALTH CARE ACT
THE DECLARATION OF DEATH ACT

The New Jersey Advance Directives for Health Care Act (S-1211 and its companion Assembly bill) and the New Jersey Declaration of Death Act (S-1208/A-1413) are the product of close cooperation among the Senate, the Office of Legislative Services and the Bioethics Commission. The two bills are the result of the extensive and open process of discussion and debate which has characterized the deliberations of the Bioethics Commission. Following transmittal to the Legislature and the Governor, the Commission's two legislative proposals were carefully examined and further refined by the Office of Legislative Services. The New Jersey Advance Directives for Health Care Act is sponsored in the Senate by Senator Gabriel M. Ambrosio, a Commission member. The New Jersey Declaration of Death Act is sponsored by Senator Ambrosio and in the Assembly by Assemblyman Dick Kamin, a Commission member, and Assemblyman David Schwartz, a former Commissioner. Both bills passed the Senate on March 29, 1990.

Like the General Assembly today, the Senate held extensive public hearings, receiving testimony on both bills from diverse groups and individuals representing a wide range of perspectives in our pluralistic state. Following these hearings, held by the Senate Judiciary Committee on May 8 and June 8, 1989, the bills were reported out of committee and later passed the Senate in the 1989 session.

The process of open public scrutiny and close cooperation among the Senate, the Office of Legislative Services, and the Commission represented by these bills is set forth at greater length in the Commission's comprehensive report, entitled <u>Problems</u>

and Approaches in Health Care Decisionmaking: The New Jersey Experience. This report, provided to all members of the Legislature in May 1990, also contains a detailed analysis of each provision of the advance directives for health care and declaration of death bills, as well as extensive discussion of relevant existing New Jersey law and the underlying rationale for the Commission's deliberations and recommendations. The report also contains the three sample advance directive forms developed by the Commission. In response to overwhelming demand, more than 11, 000 copies of these forms, along with informational/educational materials have been distributed to New Jersey's citizens in the past several months.

The Commission's open and public process has been an important and integral part of the Commission's deliberations, and bears further discussion. The Commission's membership has brought to the public policy process a broad spectrum of expertise, opinions and perspectives, including medicine, nursing, health care administration, law, ethics, theology, natural science, social science, the humanities, government and public affairs. (A list of all current and former Commissioners is attached.) This rich, diverse and representative body conducted six public hearings to receive testimony in the area of death and dying from health care professionals and professional associations, advocacy groups, scholars, and other New Jersey citizens. These hearings were held on November 21, 1986 (in Atlantic City), December 17, 1986 (in Newark), January 21, 1987 (in Trenton), February 24, 1988 (in Trenton), April 13, 1988 (in Trenton), and November 29, 1988 (in Princeton). Several of these public hearings were conducted throughout the day.

The Commission's first three public hearings invited general public input in the areas of death and dying. The final three invited specific responses to draft legislative proposals prior to final Commission consideration and approval. The February and April 1988 public hearings focused specifically on the proposal concerning the declaration of death. The November 1988 public hearing focused specifically on the Commission's proposal on advance directives.

The attached list sets forth those individuals who provided formal oral testimony at the public hearings. The Commission has also received and considered numerous written submissions from many individuals and organizations, and has regularly provided opportunity for comments from members of the public at its regular sessions. All Commission meetings have been fully open to the public, and many have been extensively reported in the media. Thus, the two legislative proposals are the result of very extensive public input and reflect ongoing effort by the Commission to recognize and respond to diverse public concerns.

The Commission and its staff would like to take this opportunity to work closely with this committee, its staff and the entire General Assembly in the same manner it was privileged to work with the Senate Judiciary Committee, its staff and the entire Senate.

New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care

Commissioners

Paul W. Armstrong, M.A., J.D., LL.M.
Chairman
Counsellor at Law

Sr. Jane Frances Brady
Vice-Chairman
President, St. Joseph's Medical Center
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Senator - District 36

Rabbi Shmuel Blech
Rabbi, Lakewood, New Jersey

The Hon. Stephanie Bush, Esq.
Assemblywoman - District 27

The Hon. Gerald Cardinale, D.D.S.
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(representing the N. J. Association of Non-Profit Homes for the Aging)

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Assistant Public Advocate
(representing the Public Advocate)

Harold George, Esq.
Ombudsman for the Institutionalized Elderly

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President, Stopwatch, Inc.

Noreen Haveron, R.N., B.S.N.
Acting Nursing Supervisor, Nutley Nursing Service

Lois Hull
Director, Division on Aging
(representing the Commissioner of Community Affairs)

The Hon. C. Richard Kamin
Assemblyman - District 23

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Rabbi, Temple Emanu-El

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Executive Director of Nursing, Overlook Hospital

Rita Martin
Legislative Director
N.J. Citizens Concerned for Life

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Associate Professor (Medical Ethics)
University of Medicine and Dentistry of New Jersey-
Robert Wood Johnson Medical School

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Director, Division of Advocacy for the
Developmentally Disabled
(representing the Public Advocate)

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Associate Professor, Nursing and Surgery,
University of Medicine and Dentistry of New Jersey
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Michael Nevins, M.D.
Internist, Chairman, Bioethics Committee,
Pascack Valley Hospital

Anne Perone, Esq.
Attorney

Robert L. Pickens, M.D.
Vice-Chairman, Bioethics Committee
Medical Society of New Jersey

David Rogoff
Director, Haven Hospice,
John F. Kennedy Medical Center

Joan Scerbo
Legislative Aide

Mary S. Strong
Chair, Citizens' Committee on Biomedical Ethics

Edward Tetelman, Esq.
Assistant Commissioner for
Intergovernmental Affairs
(representing the Commissioner of Human Services)

Harris Vernick, M.D.
Internist

Former Commissioners

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Acting Ombudsman for the Institutionalized Elderly

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Senator - District 27

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Administrator, Delaire Nursing & Convalescent Center
(representing the N. J. Association of
Health Care Facilities)

Jack R. D'Ambrosio, Esq.
Ombudsman for the Institutionalized Elderly

The Hon. Thomas Deverin
Assemblyman - District 20

David Eckstein, M.D. (deceased)
Chairman, Committee on Biomedical Ethics of the
Medical Society of N.J.

Martin Epstein, M.D.
Chief Medical Consultant, Dept. of Human Services
(representing the Commissioner of Human Services)

Robert Fischer, D.D.S.
Acting Chief Medical Consultant, Dept. of Human Services
(representing the Commissioner of Human Services)

Franklyn Gerard, M.D.
Vice-Chairman, Board of Trustees,
University of Medicine and Dentistry of New Jersey

Donald L. Gilmore
Administrator, Wiley Christian
Retirement Community
(representing the N. J. Association of Non-Profit
Homes for the Aging)

Rev. Robert E. Harahan
Chairman, Pastoral Theology Department,
Seton Hall University

Rev. Ernest S. Lyght
Pastor, St. Mark's United Methodist Church

Elmer Matthews, Esq.
Counsel to the New Jersey Catholic
Conference of Bishops

Rev. Marvin McMickle
Pastor, St. Paul's Baptist Church

Lois Mulcahy, R.N.
Administrator, Mercerville Nursing and
Convalescent Center
(representing the N. J. Association of Health
Care Facilities)

Daniel F. O'Connell, Esq.
Partner, Shanley & Fisher

Hector Rodriguez, Esq.
Ombudsman for the Institutionalized Elderly

Linda Rosenzweig, Esq.
Director, Division of Mental Health Advocacy
(representing the Public Advocate)

John H. Rutledge, M.D., J.D. (deceased)
Deputy Commissioner of Health
(representing the Commissioner of Health)

The Hon. David Schwartz
Assemblyman - District 17

William I. Strasser, Esq.
Partner, Donohue, Donohue, Costenbader
& Strasser

The Hon. Gary Stultragher
Assemblyman - District 3

E. John Walzer, Esq.
Regulatory Officer, Dept. of Human Services
(representing the Commissioner of Human Services)

The Hon. Karl Weidel
Assemblyman - District 23

Raymond Wolfinger, Esq.
Office of Legal and Regulatory Liaison
(representing the Commissioner of Human Services)

Ann Zahora
Director, Division on Aging
(representing the Commissioner of Community Affairs)

Public Hearing Witnesses

November 21, 1986
Craig Becker, Vice President/Director of Government Relations, New Jersey Hospital Association
Timothy Ames, M.D., Philip Barber Family Health Center, Lambertville, New Jersey
Ruth Theis, B.S.N., Executive Director, New Jersey Hospice Organization

December 17, 1986
Alan J. Weisbard, Esq., as a citizen
David Price, Ph.D., Chair, Ethics Committee, Dept. of Pediatrics, UMDNJ
Robin Ince, Medical/Surgical Clinician, Union Hospital, Union, New Jersey
Catherine H. Pignatello, Administrator of Professional Services, West Essex Community Health Service
Rev. Joseph W. Kukura, Vice President, Ministry and Ethics, Health Corporation, Newark, New Jersey
Richard Traynor, Esq., Traynor and Hogan, Morristown, New Jersey
Kendall Sprott, M.D., Pediatric Intensive Care Unit, Children's Hospital, Newark, New Jersey
Rubin Fernandez, R.N., Vice Chair, Ethical Practice Committee, New Jersey State Nurses Association
Russell I. McIntyre, Th.D., Robert Wood Johnson Medical School, UMDNJ

January 21, 1987
Vincent Maressa, Executive Director, Medical Society of New Jersey
John Tomicki, President, New Jersey Right to Life Committee
James Cunningham, Executive Director, New Jersey Association of Health Care Facilities
Lois Forrest, Administrator, Medford Leas Retirement Community
William Reitsma, R.N., Executive Director, Transplant Foundation of New Jersey, Inc.
Ray Waters, President, Special Needs Involvement Project, Tinton Falls, New Jersey
Ruth Theis, B.S.N., Executive Director, New Jersey Hospice Organization
Diane Mikell, R.N., Muhlenberg Regional Medical Center
Rita Martin, Citizens Concerned for Life, Trenton, New Jersey
Diane Czerepuszko, L.N.H.A., Administrator, Delaire Nursing and Convalescent Center, Linden, New Jersey
Dorothy Franklyn, Administrator, Valley Nursing Home

February 24, 1988
David Zweibel, Esq., Director of Government Affairs, Agudath Israel of America
Craig Becker, Vice President/Director of Government Relations, New Jersey Hospital Association
James Cunningham, Executive Director, New Jersey Association of Health Care Facilities
Ruth Theis, B.S.N., Executive Director, New Jersey Hospice Organization
Robert Bayly, M.D., Medical Director, ICU, Muhlenberg Hospital
Diane Mikell, R.N., Director of Quality Assurance, Muhlenberg Hospital
Joseph Stanton, M.D.
M. Rose Gasner, Esq., Society for the Right to Die
Giles Scofield, Esq., Concern for Dying
John Tomicki, Executive Director, New Jersey Right to Life Committee
Marie Niemeyer, Legislative Director, New Jersey Right to Life Committee
Patricia Coyle, Assistant Legislative Director, New Jersey Right to Life Committee
Reverend Monsignor Aloysius Welsh, representing the New Jersey Catholic Conference

April 13, 1988

Henry R. Liss, M.D., Overlook Hospital
Stewart Fox, M.D., Morristown Memorial Hospital
Anne Perone, Esq., Counsel, New Jersey Right to Life Committee
T. Patrick Hill, Director of Public Information, Citizens' Committee on Biomedical Ethics
Mary Lartolla, President, Medical Ethics Education and Legal Defense Fund, Inc.
Richard Traynor, Esq., President, New Jersey Right to Life Committee
Margaret Dedrick, New Jersey Dietetic Association
Don Perdue, as a citizen
Jerry Belsh, M.D., Robert Wood Johnson University Hospital
Babette Pachence, M.D., Lawrenceville, New Jersey
Joseph Ryan, M.D.
Mrs. Jeryl Turco-Maglio, Lincoln Park Convalescent Center
Pat Mahoney, as a citizen
Madeline Schwartz, Joan Slinger, Charlotte Kalamar, as citizens
Ann Farese, Lincoln Park Convalescent Center
Margaret Curran, Officer, New Jersey Advocate for the Disabled

May 11, 1988

Gary Skoloff, Esq., member of the law firm of Skoloff and Wolfe
Lorraine Abraham, Esq.
Harold Cassidy, Esq., member of the law firm of Cassidy, Despo, Foss and San Filippo
Professor Nadine Taub, Professor of Law, Rutgers Law School, Newark
Dr. Betsy Aigen, founder and director of the Surrogate Mother Program, New York
Jerrold Kaminsky, Esq.
Kathryn Quick, Resolve, Central New Jersey
Candace Mueller, New Jersey Committee for Adoption
Phyllis Chesler, Associate Professor of Psychology, College of Staten Island, City University of New York
R. Alta Charo, Esq., Office of Technology Assessment, Washington, D.C.
Bernice Davis, Director of One Church, One Child of New Jersey
Rabbi Edward Feld, Chaplain, Princeton University Hillel Society
Reverend Elizabeth Maxwell, St. Matthew's Church, Paramus, New Jersey
Allison Ward, Concerned United Birth Parents
Patricia Coyle, New Jersey Right to Life Committee

November 29, 1988

Ruth Theis, B.S.N., Executive Director, New Jersey Hospice Organization
William Bolan, Executive Director, New Jersey Catholic Conference
M. Rose Gasner, Esq., Society for the Right to Die
Giles Scofield, Esq., Concern for Dying
Anne Perone, Esq., Counsel, New Jersey Right to Life Committee
John Tomicki, Executive Director, New Jersey Right to Life Committee
James Cunningham, Executive Director, New Jersey Association of Health Care Facilities
Kaye Quigley, American Association for Senior Citizens

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POSITION PAPER
NEW JERSEY ADVANCE DIRECTIVES FOR HEALTH CARE ACT
(S-1211 and its companion Assembly bill)

The New Jersey Advance Directives for Health Care Act (S-1211) is sponsored by Senator Gabriel Ambrosio (a Commission member), and was passed by the New Jersey Senate on March 29, 1990. The same bill (S-3320) also passed the New Jersey Senate in the 1989 session. Senate bill 1211 and its companion Assembly bill have been assigned to the Assembly Judiciary Committee.

The Advance Directives for Health Care Act would provide a carefully crafted and comprehensive approach to "living wills" and "medical durable powers of attorney" which would allow competent adults to specify in writing their treatment preferences and to entrust a family member or friend with legal authority to carry out their wishes and to make health care decisions on their behalf in the event of subsequent decisionmaking incapacity. The bill would clarify existing uncertainties regarding the legal status of advance directives and the obligations of health care professionals to honor such documents. Advance directives are currently recognized by statute in 45 states and the District of Columbia. The bill goes beyond most existing legislation in other states in a number of important respects, including its applicability to a broad range of health care decisions; its commitment to a shared decisionmaking process among patients, families, health care representatives, physicians and other health care professionals; its recognition that patients should be permitted to request the continued provision of life-sustaining measures as well as the foregoing of life-sustaining measures; its respect for the individual conscience of health care professionals; and its readiness to confront and address the appropriate role of societal interests and concerns regarding the foregoing of life-sustaining measures.

In the view of the Bioethics Commission, the proposed legislation sets a new standard in this difficult area, enhancing New Jersey's reputation as a national leader in addressing legal and ethical dilemmas in the delivery of health care. This bill is a product of extensive and open public deliberations and reflects the Commission's approach to bioethical issues: an open-minded search for responses to complex and difficult problems in a manner that respects the diverse moral and religious views of a wide range of New Jersey's citizenry.

The New Jersey Advance Directives for Health Care Act is supported by an exceptionally large coalition of diverse and prestigious organizations and institutions (see attached list).

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EXECUTIVE DIRECTOR

SUPPORTERS OF THE ADVANCE DIRECTIVES FOR HEALTH CARE BILL
(S-1211 and its companion Assembly bill)

As of November 15, 1990, the following organizations and institutions support S-1211 and its companion Assembly bill, the Advance Directives for Health Care bill:

1) American Association of Retired Persons (AARP)
2) American College of Physicians (New Jersey Chapter)
3) Citizens' Committee on Biomedical Ethics
4) Committee on Biomedical Ethics of the Medical Society of New Jersey
5) Older Women's League (Central New Jersey)
6) Department of Health
7) Department of Human Services
8) New Jersey State Board of Medical Examiners
9) Office of the Ombudsman for the Institutionalized Elderly
10) Office of the Public Advocate
11) Office of the Public Guardian for Elderly Adults
12) New Jersey Association of Health Care Facilities
13) New Jersey Association of Non-Profit Homes for the Aging
14) New Jersey Bar Association
15) New Jersey Home Health Agency Assembly
16) New Jersey Hospice Organization
17) New Jersey State Nurses Association
18) Memorial Society of Monmouth and Ocean County
19) Memorial Society of Morris County
20) Memorial Society of South Jersey
21) Plainfield Memorial Society
22) Princeton Memorial Association
23) Raritan Valley Memorial Society
24) The Medical and Dental Staff of the Medical Center at Princeton
25) The Robert Wood Johnson University Hospital
26) Bergen County Medical Society

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POSITION PAPER
NEW JERSEY DECLARATION OF DEATH ACT (S-1208/A-1413)

The New Jersey Declaration of Death Act (S-1208) is sponsored by Senator Gabriel Ambrosio (a Commission member), and was passed by the New Jersey Senate on March 29, 1990. The same bill passed the New Jersey Senate in the 1989 session (S-2659).. The companion bill (A-1413) is sponsored by Assemblyman Dick Kamin (a Commission member) and Assemblyman David Schwartz (a former Commissioner). The bills have been assigned to the Assembly Judiciary Committee. In the 1989 session this same bill (A-3399) was released by the Assembly Judiciary Committee. The New Jersey Declaration of Death Act is virtually identical to the proposal recommended by the New Jersey Bioethics Commission in June of 1988.

The New Jersey Declaration of Death Act codifies existing New Jersey case law by providing a statutory basis for declaring death on the grounds of total and irreversible loss of all functions of the entire brain, including the brain stem (commonly known as "whole brain death"). In two important respects, the bill is unique among whole brain death laws currently in force by statute or court decision in 49 states across the country. First, the bill would mandate the adoption by law of uniform criteria for the determination of whole brain death, by requiring the Department of Health and the Board of Medical Examiners to adopt rules and regulations setting forth currently accepted medical standards, including criteria, tests and procedures, to govern such determinations. The bill requires that these standards be periodically reviewed and updated to keep pace with developments in medical technology. Second, the bill expresses an important commitment to respect for religious and moral values by recognizing the legal right of an individual to claim an exemption from the application of neurological criteria for determining death if such a declaration would violate that individual's personal religious beliefs or moral convictions. If adopted, New Jersey would be the first state to recognize such an exemption in its statutory law.

A product of extensive and open public deliberations, the bill reflects the Commission's approach to bioethical issues: an open-minded search for responses to complex and difficult problems in a manner that respects the diverse moral and religious views of a wide range of New Jersey's citizenry. (Please see attached list of supporters.)

State of New Jersey

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SISTER JANE FRANCES BRADY
VICE-CHAIRMAN

ROBERT S. OLICK, ESQ.
EXECUTIVE DIRECTOR

SUPPORTERS OF THE DECLARATION OF DEATH BILL
(S-1208/A-1413)

As of November 15, 1990, the following organizations and institutions support S-1208/A-1413, the New Jersey Declaration of Death bill:

Agudath Israel of America
Bergen County Medical Society
Department of Health
New Jersey State Board of Medical Examiners
New Jersey State Nurses Association
Office of the Public Advocate

#1 of a series of educational materials:

Understanding Brain Death

prepared for the Commission by Jerry M. Belsh, M.D.

Most of us have heard the term brain death. And, unfortunately, some of us have known relatives or friends who have been declared brain-dead. However, the meaning of the term and its relationship to our traditional understanding of death may be unclear. The purpose of this pamphlet is to explain in layman's terms the concept of brain death and how this concept influences the activities of physicians in treating severely brain-damaged patients and declaring death.

Since earliest times, death was determined when a patient's breathing and heartbeat permanently stopped. And, in the era prior to mechanical ventilators and other life-support systems, death was usually quite clear to doctor and family. If a person stopped breathing or his heart stopped beating it was certain that his entire cardiac, respiratory and brain functions would come to a halt. When these organs stopped functioning, the entire body would begin a process of disintegration and decay, thus reassuring physicians that the person was indeed dead.

In today's modern hospital, technological advances in life support systems have become commonplace, resulting in advances in patient care unheard of just a short time ago. Mechanical ventilators, cardiac pacemakers, medication to support circulation and heart function, and mechanical or transplanted organs have all contributed to our ability to prolong life. However, the use of this same technology has resulted in situations where patients have lost major signs of life (such as brain function), while other presumed signs of life (heartbeat and breathing) are being artificially maintained. Patients may suffer total and irreversible loss of all brain functions as a result of hemorrhage, trauma, tumor, or lack of oxygen related to cardio-pulmonary arrest. Yet, emergency and intensive care personnel can often maintain or re-establish heartbeat and breathing with the help of technological support despite the absence of brain functions. In cases like these, physicians realized the determination of death was not as clear-cut as it had been in the years prior to mechanical ventilators. Such cases caused the medical, legal and religious communities to re-evaluate and more precisely define how death is determined.

Over the last 25 years the dilemma of how to deal with these unfortunate cases has largely been resolved. Beginning with the report on brain death by a distinguished Harvard Medical School committee in 1968 and proceeding with the guidelines on death determination issued by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behaviorial Research in 1981, widespread national agreement has evolved among medical and legal experts concerning determination of death in the brain-damaged patient. These experts agree that the total and irreversible absence of all functions of the entire brain means death of the individual, even if mechanical support systems can sustain the heart and lungs.

In the following pages are answers to some of the most frequently asked questions concerning brain death.

Questions & Answers About Brain Death

1. What is brain death?

The term brain death, first used in 1968, means that a human's brain has permanently stopped functioning while the heart is kept beating with the aid of machines and drugs. It is used to describe the death of a patient due to total and irreversible destruction of all functions of the entire brain. Death is determined this way only when a patient's respiratory and circulatory systems are being artificially maintained in an intensive care unit. For such a patient the brain death standard is used to determine death.

2. Is the death in the term "brain death" the same as traditional cardiopulmonary death (i.e., death when heartbeat and breathing stop?)

Yes. Death is generally considered an event where functioning of the human being or "organism as a whole" has permanently ceased. Once death occurs an individual can no longer integrate the various organ systems of the body nor respond to his or her internal or external environment. These functions are controlled by the brain, the critical organ which, unlike the heart or lungs, can never be replaced.

For these reasons death is the same whether it is determined by neurological testing of brain function (as with brain damaged patients on ventilators) or by bedside testing of cardiopulmonary function (as with all other patients). Once the cardiopulmonary system- whether artificially supported or not- has permanently ceased to function, the brain no longer receives oxygenated blood and likewise ceases to function. In both situations (cessation of brain functioning despite heartbeat and the more common cessation of cardiopulmonary functioning), the result is death of the human organism. When death is declared according to neurological criteria all life support measures may be discontinued.

3. What functions of the brain cease with brain death?

All functions of the brain have permanently ceased when the patient is determined dead. This includes functions of both the cerebral hemispheres ("upper brain") and of the diencephalon and brainstem ("lower brain"). Functions of the upper brain include cognition, memory, voluntary control of movement, and capacity for experiencing emotions and pain. Functions of the lower brain include breathing, circulation, temperature control, and integration of organ systems. The brainstem also controls eye and facial movements, chewing, yawning, swallowing, and several other "brainstem reflex" movements. Consciousness is controlled by the interaction of the cerebral hemispheres with the diencephalon and brainstem.

4. What tests are utilized to determine if a patient is brain dead?

Prior to testing for brain death potentially reversible medical conditions such as drug intoxication, low blood pressure, or extremely low body temperature must be searched for and either treated or ruled out. Once these conditions have been eliminated testing for brain death is then appropriate. Over the years, a set of tests has been developed which reliably determines that all brain functions have irreversibly ceased. Although there are some minor variations among hospitals and physicians, all testing requires demonstration of the following: (1) the patient must be completely and persistently unresponsive; (2) brainstem reflexes (e.g., eye response to light, gag response to tracheal suctioning) must be absent; (3) there must be no spontaneous breathing. Most hospitals require that these sets of tests be administered twice. The period of time between testing varies depending on the suspected cause of the injury and other factors.

In addition, certain hospitals or individual physicians may require a laboratory test to confirm the absence of brain functions. This lab test is usually either an electroencephalogram (EEG) or a cerebral blood flow study. The EEG records brain activity on paper when the brain is functioning; the EEG is essentially flat when the brain is not functioning. The cerebral blood flow test measures blood flow to the brain and will record essentially no flow when the brain has ceased functioning.

5. How reliable are these tests?

Based on extensive medical experience over the last 15 years, these tests have proven to be totally reliable in identifying the brain-dead patient and only the brain-dead patient. In the words of one expert, "the validity of the criteria [i.e., brain death tests] must be considered to be established with as much certainty as is possible in biology or medicine."

6. What is coma?

Coma is a state where the patient appears to be sleeping but cannot be aroused to open the eyes or perform any purposeful movements. Coma is usually caused by a severe abnormality of the brain caused by disease or injury. Depending on the extent and severity of brain damage, the patient may or may never recover or "wake up". Because individuals determined to be brain dead according to the tests described above have permanently lost all functions of the entire brain they cannot wake up. These individuals are not in a coma but, in fact, are dead.

7. What is persistent vegetative state?

The term persistent vegetative state (PVS) describes the condition of a patient who has lost all functions of the cerebral hemispheres or upper brain (e.g., cognition, memory, ability to experience pain and emotion) but maintains all or some functions of the brainstem (e.g., breathing, eye opening, chewing). Such patients may appear to be awake, but they are not aware of and do not interact in any meaningful way with their environment. Although prognosis for any recovery of cognition is excluded by this diagnosis, these patients exhibit some signs of brain functioning and are certainly not dead. With the help of excellent nursing and medical care, patients can be sustained in this condition for many years.

8. Are there laws concerning brain death?

As of April 1990, 44 states have so-called brain death statutes, and 5 others have recognized brain death in their case law. Thus, 49 states recognize by law that a patient may be determined dead based on neurological testing. Brain death standards have been widely accepted by the medical community across the nation for many years and guidelines for brain death determination were published in 1981 by the distinguished President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behaviorial Research.

9. What is the stance of the major religions regarding brain death?

Most religious traditions recognize that irreversible cessation of total brain functioning (i.e., brain death) indicates death of the human being. Some traditions do not recognize brain death criteria and continue to rely on the traditional criteria of cessation of heartbeat and breathing in determining death. Family members are encouraged to discuss religious aspects of death determination with the patient's physician, a member of the clergy or hospital chaplain.

10. How are the topics of brain death and organ transplantation related?

Transplantation of a viable heart, kidney, lung, liver, or pancreas into a sick patient is often the only way of providing a renewed and healthy life to that patient. The major and sometimes only source of such transplantable organs are those severely brain-damaged patients who are determined dead by neurological testing but not all brain dead patients are suitable organ donors. It should be absolutely clear that no organs are to be removed from such a patient unless (1) the patient meets all accepted medical criteria for brain death; (2) the patient indicated a desire when living to make an organ donation upon his or her death by completing an organ donor form or,(3) in the absence explicit patient consent, there is informed consent by the family. Individuals interested in making a gift of their organs should contact their local hospital or the State Department of Health for information concerning organ donation and where to obtain organ donor forms.

TESTIMONY
DELIVERED TO ASSEMBLY JUDICIARY COMMITTEE
NOVEMBER 15, 1990
BY RABBI SAMUEL BLECH
IN SUPPORT OF BILL A1413 -
DECLARATION OF DEATH ACT, INCLUDING A PERSONAL EXEMPTION

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November 15, 1990

MADAM CHAIRWOMAN AND MEMBERS OF THE COMMITTEE:

My name is Rabbi Samuel Blech. I am a clergyman from the central section of our state and serve as a chaplain in a 230 bed nursing facility. I am a professor of Biblical Law and Biomedical Ethics in a Theological Seminary and a Governor's appointee to the Bioethics Committee, of which I am a member of the Executive Committee and chair the Task Force on Protecting the Vulnerable. Thank you for the opportunity to testify before you on behalf of the legislative initiative being studied today.

The New Jersey Declaration of Death Act (Bill A1413), as you know, is a result of over two years of intensive deliberation and debate. It is an historic piece of legislation that all who share in its creation sensed throughout this experience. It is no doubt also flawed, as any important legislation might be; but it is, nevertheless, the product of a sincere effort on the part of a group of dedicated men and women of which I am proud to have been numbered.

The vast majority of states across the country have legislated neurological criteria or "Brain Death," as it is popularly called, as an acceptable pronouncement of death by medical professionals. We in New Jersey have an opportunity to once more put into place a piece of legislation which will not only be a rubber stamp, following the example of others, but will rather serve as a thoughtful and insightful model for others to follow.

It is particularly significant to note that we in New Jersey were wise in allowing ourselves to wait - under great pressure- until the dust had settled. This allowed us to observe states where similar legislation had already been enacted and to benefit from the collective experience which that engendered. The temptation to quickly follow suit and avoid the appearance of dragging our feet, especially in light of our state's role as a pace setter for the entire nation in issues of this nature, was enormous. It <u>did</u> allow for an extremely diverse group of scholarly people to carve out a singular document which stands as a model of sensitivity and concern for <u>all</u> the citizens of our state, again establishing a precedent to be followed by others.

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The personal and religious exemption which not only allows for the acceptance of new criteria in the pronouncement of death, but continues to recognize the traditional format as well, is probably the element which invites the most attention.

We, as a group, in our deliberations, came to the conclusion that to accept new criteria is to broaden the concept rather than to reject the traditional mode by which many cultures declare their dead, as has been true for thousands of years. We ought not deny those who have a personal or religious reason for interpreting death as their forebears did their rights of protection under the law. This approach runs much closer to the ever greater recognition of individual autonomy in medical decision making.

Ideological concerns from a segment of the medical community - and I am confident that it is a small segment - that continued acceptance of traditional criteria perpetuates an archaic concept-rings hollow and must, at best, be viewed as being cavalier and shallow. The health care providers - as well as lawyers and clergymen, for that matter - are and always should be open to considerably more than the narrow confines of their own disciplines. They, and professionals in other fields as well, cannot claim infallibility; they possess the same shortcomings common to us all. This dictates that we must move gradually in reshaping the historical legacy endowed to us by several thousand years of civilization. The practice of medicine has its breathtaking highs - tempered, if not diminished, by its dismal and often fatal failures. We in the Commission were mindful of the need to recognize this truth and seek to earn the trust and confidence of our citizens by allowing for free expression of personal preferences rather than dictate.

The additional concern of those involved in transplant work, that maintaining traditional criteria might undermine the acceptance of neurological criteria in the Declaration of Death, is, in my opinion, also unfounded. Quite the opposite! Insisting in the dramatic departure from deeply held principles which have spanned the millenia must, by its very nature, foment distrust. Allowing for gradual awareness through educational processes and a tolerance for diversity only contributes to credibility and acceptance.

As to the further concern that our health care system cannot easily tolerate a two-track approach for the sake of uniformity and imposes undue stress on caregivers, I think it important to clarify this as well. The Bioethics Commission, which includes some of the most prestigious and knowledgeable experts in the field of healthcare, as directors and adminstrators of medical centers, hospitals, long-term care facilities - themselves doctors and nurses, public health officials and others - unanimously agreed that this would not be a problem that would or should stand in the way of retaining the original format for the Declaration of Death.

In addition, as disquieting as it may be, I must draw an inference from the great controversy left in the wake of Roe v. Wade. No matter on which side of this volatile issue one stands - and I have very strong personal and theological feelings about this issue - the legal acceptance of abortion on demand may present a picture in obstetric units of a struggle to preserve the life of a prematurely born infant in one bed while ironically dispatching the life of a fetus in a second bed - and which the healthcare community has not viewed as inconsistent. This duality, it appears to me, is much more striking and emotionally demanding of our healthcare providers than waiting the relatively short time - and I stress this, rarely more than 24 to 48 hours - between the neurological criteria and the traditional standards in the Declaration of Death, hardly an unreasonable nor burdensome imposition on the system and its practitioners. I think that this has, perhaps, not been articluated clearly enough, because of the lay confusion between brain death - which this bill addresses - and the so-called PVS (Permanent Vegetative State) - which it does not. The oft-painted picture of doctor, nurse and family fretting over a brain dead patient for months or years utilizing valuable medical services and exhausting resources - this is a deliberate misrepresentation calculated to elicit a highly emotional yet unjustifiable response.

Many of us have been led to believe that brain dead people linger on for weeks and months, attached to machines which maintain their vital functions. This is scientifically untrue and a gross distortion of fact. The systems of a brain dead person deteriorate rapidly despite all mechanical support - meaning that the time until traditional criteria for death sets in is relatively short.

The legislation before you, therefore, finds that allowing for personal autonomy does not unduly infringe upon nor burden the healthcare system and respectfully allows for the free expression of all the citizens of our state. We wish to encourage its endorsement by your committee, Madam Chairwoman, and its release and passage on the floor as did the Senate.

Might I add, just to underline the seriousness of the work and decisions that lay ahead of us: consider what two Nobel laureates have written concerning issues of this kind. The first is James Watson, of DNA DOUBLE HELIX fame. He said, " If a child were not declared alive until three days after birth, then all parents could be allowed the choice only a few are given under the present system. The doctor could allow the child to die if the parents so choose and save a lot of misery and suffering. I believe this view is the only rational, compassionate attitude to have." The other quote is that of Francis Crick, who said, "No newborn infant should be declared human until it has passed certain tests regarding its genetic endowment and that if it fails these tests, it forfeits the right to live."

Perhaps these two statements most dramatically warn us of the approaches that lay ahead. We must proceed with great caution, with the full realization of the enormous consequences that our decisions may effect.

Again, thank you for giving me the opportunity to share my thoughts with you, and may our labors be blessed with success.

Rabbi Samuel Blech
RABBI SAMUEL BLECH

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TESTIMONY

On

"NEW JERSEY ADVANCE DIRECTIVES FOR HEALTH CARE ACT"

S-1211 And A16

TESTIMONY OF ANNE M. PERONE

The proposals which are before this committee are premature and have been prepared in a vacuum. The enabling statute, P.L. 1985 Ch. 363 of the New Jersey Legislature required that the Bioethics Commission shall:

3(b) Gather data about how New Jersey and other jurisdictions handle decision making regarding the termination and refusal of care and treatment.

Where is this data? Where are the reports?

Further, the Commission had a duty to:

3(c) Assess the need for additional programs and services relating to medical decision making.

Where is this data? Where are the reports?

Finally, the enabling statute provides in Par.6:

"The commission shall ...make its report to the Governor, Legislature and public.... The initial report ... shall include:

a. A report on the current status of the law in New Jersey and other jurisdictions regarding the termination of treatment, surrogate decision making, and related issues;

b. An examination of existing practices and procedures for decision making, such as Quinlan ethics committees and Grady and Conroy procedures, and a determination of how well they work and where change is needed...."

Where is the data? Where are the reports?

The commission has provided no such report of current practices and procedures, or how New Jersey and other jurisdictions handle medical decision making, or any assessment of a need for change,and no reports regarding how well current practices work.

Rather the Commission just forged ahead , putting the "cart before the horse" ignored the mandate of the New Jersey legislature and prepared the S-3320 proposal.

Even S-3320 states on page 24 that, "This commission was established by the Legislature in 1985 to

> provide a comprehensive and scholarly examination of the legal and ethical dilemmas in the delivery of health care posed by modern advances in science and medicine."

Where is the report of the required scholarly examination?

No studies or reports of practices in hospitals or nursing homes in New Jersey have been done. The Commission has not followed its mandate. It jumped right into preparing living will legislation without providing the necessary framework that was required.

In addition to opposing this legislation because it did not follow the legislature's mandate to study and to report on the use of advanced directives in other jurisdictions and in New Jersey , the commission was to report on whether the use " has promoted the preservation of life" among other issues. Par.6 (f) provided that "Accompanying the reports, the commission shall submit any proposed legislation which it may desire to recommend for enactment"

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By not providing the mandated reports to the public, to the Governor and to the Legislature, this proposal is premature and fatally flawed.

IT IS DANGEROUS

The major protection that is granted by a living will is not to the patient but to the doctors/professionals/ institutions. Complete immunity is granted to doctors, and institutions from civil, criminal and professional liability. No profession or livelihood has ever been afforded such sweeping and complete immunity.

Every carpenter, builder, lawyer, doctor is held liable for their negligence or malfeasance. Patients are not gaining any civil rights ----they are losing their rights to proper, beneficial, caring medical treatment.

A person granted "power-of-attorney" over the financial affairs of a patient is still liable for abuses of the fiduciary relationship between the principal and the agent. The powers of attorney are spelled out and he/she must follow the powers granted. If a patient wants to grant complete immunity to his/her attorney-in-fact, then it can be granted by each individual in their own document.

Sweeping legislation granting across-the-board immunity is dangerous and does not protect the patient.

Patients normally sign a one-page Living Will document. They are usually not informed of the language in the statute giving complete immunity. The elderly and the nursing homes

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are being sold a bill of goods regarding the "benefits of this legislation". Rather then gaining a right, the patients are losing protection of the law.

Another danger in this proposal is that our well-meaning citizens and legislators are being lulled into believing that somehow this legislation is giving them protection which is not all ready in place. This is not the case. Patients and families have common law rights, they have rights under the power of attorney statites in place.

A "living will" is not the end product of a "rights" movement--it is the <u>means</u> to an end.

The "Living Will" was formulated in 1967 by the Euthanasia Educational Council (now called Concern for Dying) as a tool to promote acceptance of euthanasia. Because the public was not yet ready to accept the total concept of euthanasia, it was intended that the document would gradually shape public opinion, thus leading to a recognition of the "right" to choose when, where, why and how to die.

All "Living Will" legislation currently in effect allows for involuntary euthanasia and assisted suicide. No "Living Will" legislation excluded medications upon which a patient was previously dependent (insulin, digitalis, etc.) from the categories of medical procedures which can be withdrawn or withheld. The "Living Will" allows for euthanasia by omission of even necessary and ordinary care, such as removal of food and water.

The next step toward full acceptance of the "right to choose" death-on-demand is the proposal for euthanasia by commission--already initiated with the introduction of the "Humane and Dignified Death Act" which would allow for "physician administered aid in dying (lethal injection)." It is significant that this act was initially introduced in California, the first state to pass "Living Will" legislation, and that it is not new legislation but is, instead, being proposed as a series of <u>amendments</u> to existing "Living Will" legislation. Currently, bills to pass "aid-in-dying" are being introduced in Florida, Arizona, Oregon, California and other states. A Living Will is not the <u>end</u>; it is the "means to an end" - death on demand!

In California, although the "aid in dying" people state that 60% of the people want this legislation, they could only get 200,000 signatures out of the entire population of California, when they tried to get an amendment on the ballot. Euthanasia proponents declare there is a <u>need</u> and a demand for this legislation, when they are the ones demanding it.

After the 1960's, the Euthanasia Society of America (now known as the Society for the Right To Die), and the Education Council (now called Concern for Dying) decided to create a climate in which euthanasia legislation would be possible. The "Living Will" was the suggestion of Luis Kutner at the 1967 Euthanasia Society meeting - as a means for creating such a climate.

Abby Van Buren, a long time euthanasia advisory board member, promotes Living Wills regularly in her column.

A slow, steady, inch-by-inch movement with carefully constructed language (for acceptability) has progressed from California to New Jersey.

Euthanasia advocates sugarcoat the bitter pill of euthanasia by using acceptable language for the unacceptable.

Titles such as "Right to Die Act" (N. Mexico); "Death With Dignity Act" (Delaware); "Rights of the Terminally Ill Act" (some states). Each word is weighed carefully by euthanasia proponents for its impact on any opposition.

Common phrases founded in living wills are "my attending physician"; "unable to make treatment decisions"; "final stages of a terminal condition"; "death is imminent", and "life sustaining procedures".

A Living Will signer assumes a particular meaning for each of these phrases. But how are they, and how can they be interpreted?

The general understanding of "attending physician" is a physician in whose care one has been for some time. In realty, "attending physician" refers to the physician who happens to be in charge of a person's care at a particular moment. It is entirely possible that, within the course of a day, a hospitalized patient could have as many as three or more attending physicians, any one of whom could put a Living Will into effect.

While the signer of a Living Will may think "unable to make treatment decisions" means that one is in a coma, the

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words can be interpreted to mean that one is mildly senile. No Living Will law gives any objective-criteria for making the determination that the patient can't make these decisions. The individual attending physician can make this crucial judgment based upon purely subjective considerations.

Picturing "final stages," one may assume this means the last few days of life. However, "final stages" is rarely defined in legislation and, when it is, it is described as meanig that death will occur in a "reasonably" or a "relatively short time," interpreted as meaning days, weeks, months or longer, varying from illness to illness and patient to patient.

"Life-sustaining procedures" are generally perceived as respirators, heart-lung machines and other advanced technological procedures. In fact, "lift-sustaining procedures" have been interpreted to include medications such as insulin, digitalis or antibiotics.

These phrases are not the only illusory protections found in Living Will legislation. In passing such legislation, many pro-life legislators have often insisted that a strongly worded statement prohibiting mercy killing be included in the law. California's Natural Death Act states, "Nothing in this article shall be construed to condone, authorize, or approve mercy killing..." But recently, new legislation was introduced to amend the California law. The amendments would allow for the provisions of "aid in dying" which means "any medical procedure that will swiftly,

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painlessly, and humanely terminate the life of the qualified patient.

Euthanasia by lethal injection would then be allowed under California's Living Will Act.

But how would this be possible under the California law with its prohibition of mercy killing? It's really quite simple. **"Aid in dying" will be an exception.** Mercy killing is still prohibited, but "aid in dying" is not to be construed, under the law, as mercy killing.

The protective words still remain. It's only the protection that's removed.

At the 1984 meeting of the World Federation of Right to Die Societies, the goals of the euthanasia movement were clearly outlined--goals culminating in the establishment of suicide clinics where anyone can request "self-deliverance."

In order to reach this final goal, the steps of acceptance of the Living Will, legalization of assisted suicide and the lethal injection for the terminally ill must first be taken.

At that time, Professor Curt Garbesi of Loyola Marymount Law School in Los Angeles said, "We are focusing on the first short step of this process." He was referring to promotion of the Living Will. Garbesi is one of the authors of the amendments to California's Living Will Act.

At the same meeting, Dr. Helga Kuhse of Australia's Voluntary Euthanasia Society said, "We are blinded by the myth that withdrawal of treatment is morally different than

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killing." She went on to explain that once it's legal to remove all types of treatment and care, it will be a small step to obtain acceptance of direct killing, since the public will then recognize that withdrawal of some types of treatment leads to a very painful death.

"They'll realize that this is clearly not in the patient's best interest and that, given an injection, the patient could have died quickly," she said.

It appears that the euthanasia movement's agenda is moving ahead on schedule--with the help of well-meaning, unsuspecting people. It will only be stopped if we take the time and the effort to learn its language and to oppose it unequivocally.

UNNECESSARY

An Advanced Directive Law is unnecessary under the two common law Principals which currently exist.

The first

1. Requires the health care providers to provide appropriate and beneficial medical treatment, and

2. Patients are the final decision makers since and unconsented-to treatment would constitute "an unconsented to touching or battery" See W. Prosser, Handbook of Law on Torts (4th ed.) 161-164 and 34-37.

These decisions of a competent patient are always balanced and weighed against the state's interests in preserving life, preventing suicide; protection of third parties, protection of the integrity of the medical and

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health care professionals, and keeping the public's confidence in the the medical professionals and institutions, and protection of the public health.

Our state laws regarding assisted suicide and homocide are examples of our state's interest in protecting life and preventing any wrongful or irrational termination of life.

In addition to the citizen's common law rights to agree to or to refuse medical treatment, each person has a fundamental Constitutional right to life protected by the 14th Amendment. This gives the State a compelling interest in protecting the procedural and substantive due process rights of each person. The language in the advanced directives herein deny this fundamental protection.

The real purpose of a living will is <u>not</u> to protect the patient or to give the patients more rights or authority than already exist. These rights are already in existence whether the patient is competent or incompetent.

Incompetent patients have families-physicians making their medical treatment decisions. The only controversy is in rare cases where the doctor or institution refused to terminate food and fluids without a court order because of the state's opposing interests which are to prevent suicides, homicide, preserve medical integrity and confidence in the profession, etc.

Patients without relatives have the right to use the traditional and existing power-of-attorney law to have a particular person handle <u>financial matters</u>, and can also have

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that same person appointed to make medical decisions. The law is on the books in New Jersey. We don't need a living will law to appoint a person to make decisions if we are later judged incompetent. In fact on page 26 of this proposal, Paragraph 26 (b) recognizes the "right of a patient under existing law (N.J.S.A. 46:2B-8) to appoint an attorney-in-fact to make decisions, however, the present proposal rips away all patient protection.

The Supreme Court of New Jersey upheld the use of a power of attorney used by Hilda Peter for her friend to make medical decisions for her. The only problem was the document did not give her friend the right or power to withdraw food and water. In Matter of Peter by Johanning, 108 N.J. 365 (1987).

It is interesting to note that the case of Hilda Peter has been widely criticized because of allegations by the third wife of the guardian (Johanning) that he was brutal, and tried to poison her. Neighbors of Johanning's second wife stated that she had complained a week before she was found in dead, that Johanning was trying to kill her. Johanning's second wife was found under similar circumstances as Hilda Peter, with alcohal and sedatives in her system and bruises on her body.

It is unfortunate that the Supreme Court was unaware of the investigations of the guardian Johanning before it rendered its decision.

The power of attorney law as it exists however would

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permit persons to designate an agent for medical decision making, but does not take away the patient's rights for a due process hearing if the attorney -in-fact attempts to exceed his or her powers. Just as an attorney in fact is liable if he appropriates the moneys of an incompetent, he should be held liable if he does not follow the medical powers given to him.

The leading case, State v. Kennedy, 61 N.J. 509 (1972) involved a 99 year old woman who signed a power of attorney and the agent appropriated her life savings to himself. He was convicted of embezzlement and fraud. It is inconceivable that the legislature should protect an elderly woman's assets with a full due process hearing and consider removing the same kind of protection of her life.

The real purpose of a living will is not to protect the patient or to give the patients more rights or authority. These rights are already in existence whether the patient is competent or incompetent.

This bill takes away the rights of incompetent patients in many ways; which is contrary to the traditional actions of the New Jersey Legislature.

The legislature in New Jersey has always tried to protect vulnerable patients by affording them their 14th Amendment due process rights and the full protection of the law.

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For example, Developmentally Disabled Patients are protected in N.J.S.A. 30:6D-5 (a) (4), which provides:

> No person receiving services for the developmentally disabled at any facility shall: be subjected to shock treatment, psychosurgery, sterilization....without the express and informed consent of such person...if a minor or incompetent , that person's guardian ad litem shall petition a court of competent jurisdiction to hold a hearing to determine the necessity of such procedure at which the client is physically present, represented by counsel, and provided the right and opportunity to be confronted with and to cross-examine all witnesses alleging the necessity of such prcedure. In such proceedings, the burden of proof shall be on the party alleging the necessity of such procedure. In the event that a person cannot afford counsel, the court shall appoint an attorney not less than 10 days before the hearing.

N.J.S.A. 30: 6D-(b) requires every developmentally disableed person to be provided with a nutritionally adequate and sufficient diet.

Mental Patients have rights similiar to the disabled rights wherein he must be judged incompetant in a court hearing and cannot be subjected to experimental treatment or sterilization without due process protection. See N.J.S.A. 30:4-24.2 d (2).

IN the case In re Grady, 170 N.J. Super 98 (1979) parents of a Down's Syndrome child applied for permission to have their daughter sterilized. The Court held among other factors that there must be a court finding of the patient's incompetancy, that the incomptetancy was permanent, that all\ procedural safeguards have been satisfied (ie. a guardian -ad litam to represent the incompetant in court), and the patient had a right to examine all proofs and cross examine witnesses. Id. at 125-126.

It is proper and appropriate for the legislature to continue to protect the vulnerable elderly from coercion to sign a Living Will whether that coercion be by family or institutions which are mandated " to educate" all new arrivals and periodically thereafter about the so-called benefits of an early demise.

Many patients are in a depressed state due to the physiological after effects of a stroke. A full competency hearing which is currently mandated before sterilization can be performed, is certainly appropriate regarding life and death decisions.

The Child Abuse Statutes of 1984, 42 U.S.C.A. sec.5103 (supp.1985), a federal statute defining the withholding of medically indicated treatment from children born with disabilities as child neglect, require that nutrition and hydration be provided to all disabled children regardless of whether their condition places them in a category in which medical treatment is not required.

The federal legislature took cognizance of the fact that withholding or withdrawing medical treatment may not result in a patient's death, but it is impossible for a patient to survive the withholding of food and fluids. Such action is final; death is a certainty.

Many patients in a coma, or because of senility are also as dependent as an infant. Removal of food and water is a cruel and inhumane death and should never be permitted.

CONSIDER THE SOURCE OF LIVING WILLS

In 1982, at a meeting in the Countway Library of Medicine, Boston, Mass., the Society for the Right to Die Society of New York paid for and invited ten doctors to formulate policy on withholding and withdrawing medical treatment. The result of this meeting which was sponsored by the euthanasia society were published in the New England Journal of Medicine, April 12, 1984 as " The Physician's Responsibility Toward Hopelessly Ill Patients." These doctors , four of whom are board members of the Euthanasia Council concluded that "it was morally justifiable to withhold antibiotics and artificial nutrition and hydration, as well as other forms of life sustaining treatment, allowing a patient to die. They said this is permissable for patients in a p.v.s. state, or severely and irreversibly demented patients (who do not initiate purposeful activity but passively accept nourishment and bodily care)..."the physician must always bear in mind that senseless perpetuation of the status quo is decision by default."

Regarding patients categorized as" pleasantly senile"--the physician should provide emergency resusitation and intensive care sparingly, "guided by patients wishes, if known, by patient's family and assessment of patients's prospects for improvement.

Dr. Leo Alexander, who assisted at the Nurenburg trials after W.W.II. said before his death--regarding the above referenced publication, that the euthanasia climate in the United State is exactly like that in pre-Nazi Germany.

I am sure Dr. Leo JAlexander is turning over in his grave regarding the latest publications by 9 out of the same 10 doctors. "The Physicians Responsiblity Toward Hopelessly Ill Patients--A Second Look", New England Journal of Medicine, March 30, 1989. The meeting was held at the same library. The entire document was geared toward assisted suicide. All but two doctors concluded and reported "that it is not immoral for a physician to assist in rational suicide of a terminally ill person." Id. at Vol. 320, No. 13, p.848. The Right to Die Society has carefully orchestrated the 1982 and 1987 meetings which resulted in edicts by a mere ten doctors.

These ten physicians consist of four members of the Euthanasia Board and other physicians who have published pro-

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death medical articles. These two reports are no more or no less than the bio-medical beliefs of the President Emeritus of the Society of the Right to Die, Dr. Joseph Fletcher. See attached article " Indicators of Humanhood: A Tentative Profile of Man.", published by the Hasting Center in 1972. Fletcher decided that a person is not a person if he has less that a 40 I.Q.; is not self-aware (unconscious or irreversible damage to the brain); is not controlled by self; lacked sense of time or futurity , or past; not capable of relating to others; lacked concern for others; was unable to communicate; lacks control of existence (ie. degenerative psychosis); lacks curiosity (to be without affect such as many mental patients); lacks change both physically and mentally; lacks rationality.and feeling. To be fully human Fletcher argues you must be cerebral and a creature of feeling.

The Godfather of the euthanasia movement has outlined his views on what is a person. (Note non-persons lack constitutional rights) The 10 physicians in Boston at the behest and cost of the Right to Die Society have outlined the approved agenda. The Right to Die Society thought up the "living will" concept as a means to arrive at their end which is Death on demand. "Rational Suicide" will occur at clinics--called deliverance centers. One of Dr. Fletcher's famous quotes is:

> " What has taken place in birth control
> and birth selection, must take place

in death control and death selection."

My Jewish friends often say "never again" regarding the holocaust of W.W.II. where thousands of demented, disabled, retarded, vulnerable people were killed at the "mercy" of physicians and institutions.

Lately many T.V. shows have shown the Holocaust. Good people carried out many "**unacceptable actions**" when the actions and language were made "**acceptable.**" This bill is a carefully worded document to permit **unacceptable** treatment of the elderly and vulnerable in New Jersey. It is not an end in itself--but a means to an end that the proponents of euthanasia have very careullly assisted in crafting not only in New Jersey but across the United States.

You may wonder if my criticism of the euthanasia is unwarrented. Allow me to point out a few facts.

1. The Bioethics Commission had fourteen seats for appointment of members of the public. Nine out of the fourteen seats were initially held by members of / or financial supporters of the New Jersey Citizens Commitee.

2. The Citizen's Committee has conducted workshops performed plays, and shown filmstrips dealing with the economic problems of longterm care and the promotion of advance directives/ living wills at more than 300 different locations.

3. The Citizens Committee has sponsorred workshops where powerful proponents and Board members of the Euthanasia Educational Council have promoted living wills and the

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removal of protection of patients by the Ombudsman.

4. The Citizen's Committee has received hundreds of thousands of dollars from the Prudential Foundation directly \and via funnelling through the Hastings Institute. It also received huge grants from the R.W. Johnson Foundation.

5. A National Bioethics Citizen's group is in the planning stages and was also funded by the Prudential Foundation and R.W. Johnson Foundation.

The Prudential Insurance Company will certainly benefit economically for every patient who is removed from its medical insurance payment rolls. This is a fraud upon the millions of elderly patients who have paid premiums for their medical care throughout their lives.

The Robert Wood Johnson Foundation will certainly benefit economically under several proposals before the Commission.

It is time for our Legislature to take action. Send the proposals back to the Commission and demand that it provide the mandated reports and studies for which the Commission was convened.

SPECIFIC FLAWS in S-3320

2.b. States " **modern advances in science and medicine...etc."** Tubes providing nutrition and hydration are not modern or advanced. They have been in use for more than eighty years. Today, nasogastric tubes are less than 1/8 inch in diameter and are used in every medical facility and at home.

... **This State recognizes that the fundamental right of individual choice...** New Jersey has always recognized a common law right but has not decided on the basis of the Constitution that there is a "fundamental" right of individual choice in these cases.

2.c. "**patient loses decision making capacity**" How will this be determined? Will the patient be afforded a due process hearing regarding incompetency as disabled and mental patients are afforded?

2.d. "The right ...to forego life-sustaining treatment" is subject to a list of state and societal interests. How is it subject?

3. " Decision making capacity". What standard will be used to determine a patient's decision making capacity? How will it be "evaluated relative to the demands of a particular health decision? Is the standard objective or subjective?

" Do not resusitate order" Who gives the doctor the authority to write this order?

" Health care decision" Includes a decision of a patient "to refuse a transfer of care". Suppose a doctor or nurse refuse to abide by a patient's wishes, will they be required under the patient's refusal of transfer right to violate their professional conscience and/or ethical standards?

" Life sustaining procedure" according to this definition will exclude any i.v., or tube administering food,

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water, medication, antibiotics, insulin, digitalis or any other stabilizer used in certain medical situations. "thereby increase the expected life span" Every drop of insulin, or food and water or digitalis would provide an ordinary life span. The deprivation will decrease the expected life span.

"Permanently unconscious" This definition is frought with problems. Very few doctors can say a coma is irreversible. The PVS state is also a recent name for brain damaged patients. The "without limitation" language is there specifically to include demented Alzheimer patients without"capacity for interaction with the environment". It appears that Dr. Fletcher wrote this definition back in 1972.

"Terminal condition" No determination of a life expectancy is required? Why not? Of course the prognosis of life expectancy of six months or less will always be accurate "without the provision of life-sustaining treatment". Most people die in three weeks without "life-sustaining food and water". Some will die in a day without insulin.

4. Declarant may sign a Living Will at any time. If the declarant gives only a directive but does not appoint a representative, the declarent is waiving all rights to making and giving informed medical consent regarding the benefits and burdens of any and all treatment in a given situation.

5. b. (1) and 5.d. What if a patient revokes orally to one "attending physician" but fails to revoke with all subsequent medical personnel? What if the patient wants to

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revoke but can't communicate?

6.b. Instruction directives waive the patient's right to informed medical consent.

7.a.(2) A patient may lack decision making capacity temporarily because of injuries or stroke or drug overdose; does this trigger the termination of treatment?

8. Who is the "attending physician? Someone who knows the patient or one of many during the hospital day?

8.c. Mental and disabled patients will not be afforded due process rights with this language in contravention to existing statutory protections.

8.e. There are many elderly who are hard of hearing and /or speak a foreign language, how will their rights of being informed be protected?

10a. Does the attending physician have " an affirmative duty " to inquire of the patient, his family or others of a revocation? How will the attending physician gain knowledge of the modification or revocation?

10.b. It is interesting to note that a doctor's refusal to withdraw or withhold life-sustaining treatment will be protected however, the patient who is not provided the care/ medicine/ food/water to sustain his life is said to be " abandoned or treated disrespectfully" if not transferred in a timely manner for the treatment of non-treatment! George Orwell could not imagined a better example of " double speak" or "new speak". Food and water and medical treatment are abandonment! Transferring a patient to his death is

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respectful!

10.c. Ditto.

11.b. How can some patients who can not communicate for various reasons avail themselves of right to demand food and water? Does moaning qualify? Will the patient be drugged against pain so they can't communicate?

13 a.(1) Interferes with the operation of nursing homes and hospitals in that private institutions are required to inquire and thus subtlely promote living wills among its patients. The "shall adopt" language is mandatory in nature and impinges on the rights of private corporations of freedom of contract and to decide corporate policy.

13 a.(2) Interferes with the operation of an institution by requiring it to "educate" families and patients about living wills and to" assist patients in discussing and **executing** a living will!

13. a.(4) How can a an institution assure the patient is not abandoned or treated disrespectfully when the purpose of transfer is to terminate treatment?

13.a.(5) The current rules regarding disputes is easy , call the Ombudsman for the elderly in nursing homes. For all others petition the court/ expand the office of the Ombudsman. It is impractical to expect nursing homes to have an effective ethics committee when hospitals don't have them. Further, it is a duplication of many committees with varying understanding of the statute. A disinterested state appointed person / or a court of competent jurisdiction which affords proper protection in disputes.

13.b. Is inadequate since it only exempts religiously-affiliated institutions. All private institutions may be forced by this provision to either close down or forced to commit acts against the conscience of the owners, the administrators and/or the staff. All institutions should be permitted a clause protecting the conscience of the owners, administrators, and/ or staff.

13.c. This clause does not protect any institution, since a Catholic Hospital was ordered by the court to starve and dehydrate a patient to death. The Peters, Jobes, and Farrell trilogy effectively extinguished any rights of an institution to refuse to withhold or withdraw treatment unless this Legislature protects the rights which have been removed by judicial activism.

14.a. The Ombudsman should be appointed to investigate conflicts. The second level should be the Court.

15.c. There is no Constitutional right of privacy under the federal or state constitution to refuse medical treatment.

16.a.(1) Food and water is never futile in prolonging life, it's a necessity. One will never know if the death is "immenent" if food and water is removed. It is a self-fulfilling prophecy. This Par. is dangerous because it is written in the disjunctive "or" rather than the conjunctive "and". Therefore (1) or (2) or (3) all permit the removal of food and water. Patients have come out of a coma after months

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and even years. Patients have been erroneously diagnosed as P.V.S. The only situation where water is withheld for medical reasons is in severe burn cases. All other conditions allow fluids by i.v. or hyper-alimentation.

17.a. Does this mean the patient decides "Do not resusitate/ or the doctor?

17.c. What legal authority does a doctor have to write a "Do not resusitate order"?

18.a. Unnecessary duplication of time and effort. We have an Ombudsman. Expand the powers of that office.

18.b.(1) Penalty makes this unworkable. (2) and (3) O.K.

19.b. Invades and withdraws protection afforded these patients in other statutes.

20. and 21. Most dangerous. Legislature will abdicate its authority in most crucial area of patient protection. Most citizens are unaware of rules and regulations promulgated by Department of Health.

22. Complete immunity deprives patient of protection and possible life-threatening decisions. "Good faith" standard difficult to assess. Is "good faith" similar to "taking a whack at it"?

All health care professionals are immune from any liability. How many Living Will declarants in New Jersey were aware of this when they made (or shall make) a Living Will? Why absolve a complete industry from liability? No other profession is immune for its negligence. Suppose a patient executes aliving will requiring all life saving procedures? Would the health care professionals be immune from liability for failure to provide same? Under this blanket immunity, YES!

23. The absence of an advanced directive most certainly should create a presumption against assuming a patient wants the removal of treatment.

26.a.and b. Effectively remove protections afforded under the power of attorney statute.

26.c. Gives power to self-supporting youths / pregnant girls under the age of 18, the right to terminate treatment without parental interference.

29.a. and b. provides the "stick" to enforce removal of treatment if the" carrot" of immunity doesn't work.

CONCLUSION

IN CONCLUSION , I URGE THE SENATE TO REJECT THIS PROPOSAL SINCE IT IS

1. PREMATURE
2. DOES NOT COMPLY WITH THE ENABLING STATUTE
3. IS DANGEROUS
4. IS UNNECESSARY
5. IS A "MEANS" TO A EUTHANASIA "END"
   THAT IS, DEATH-ON-DEMAND
6. IS REPLETE WITH LANGUAGE FORCING A LIVING WILL
   AND A DEMAND FOR WITHDRAWAL OF TREATMENT ON
   PATIENTS, INSTITUTIONS, AND OTHER PROFESSIONALS

TESTIMONY TO THE ASSEMBLY JUDICIARY, LAW
AND PUBLIC SAFETY COMMITTEE
ON ASSEMBLY, No. 16 AND SENATE, No. 1211
by
Leonard Fishman
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General Counsel
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OVERVIEW

New Jersey is one of only five states in the country without a health care directives ("living will") statute.

At the end of 1988, the Commission on Legal and Ethical Problems in the Delivery of Healthcare (also known as the "New Jersey Bioethics Commission") approved a model living will statute. That model has been introduced in substantially the same form by Assemblyman Naples as Assembly, No. 16 and by Senator Ambrosio as Senate, No. 1211, the "New Jersey Advance Directives for Health Care Act."

A.16 and S.1211 would do more than recognize living wills in New Jersey. These bills would establish a process for health care providers to follow when implementing a living will.

The New Jersey Association of Non-Profit Homes for the Aging's (NJANPHA's) Board of Trustees, representing every major religious denomination in the State, has endorsed these bills <u>unanimously</u>. We urge this Committee to report A.16 and S.1211 favorably and promptly, with the amendments noted below.

DISCUSSION

A.16 and S.1211 would codify and build on New Jersey case law which recognizes the right of the individual to make voluntary and informed choices to accept, to reject, or to choose among alternate courses of medical and surgical treatment. That this right is fundamental and constitutional has been affirmed by the New Jersey Supreme Court, in cases from In re Quinlan to Matter of Jobes, and by the United States Supreme Court in the Cruzan case.

To preserve this right, in case an individual loses decision-making capacity, these bills recognize the right of competent adults to plan ahead for health care decisions through the execution of advance directives, such as living wills and durable powers of attorney.

Proponents of A.16 and S.1211 (and, indeed, their detractors) stress that these bills would protect the rights of individuals to control decisions about their own health care. Of great importance, but less appreciated, are the responsibilities these bills would impose on health care professionals and institutions to assure that their patients' rights are responsibly effectuated.

For example, A.16 and S.1211 would establish procedures that physicians, nurses and other health care providers must follow when implementing an advance directive.

The bills would also impose multiple responsibilities on health care facilities, which would be required to: inquire of prospective residents whether they have a living will; provide informational material to patients and their families and educate them about available treatment; inform health care professionals about their responsibilities under the act.

Decisions to accept or reject medical treatment -- including life-sustaining treatment -- are made every day in New Jersey's hospitals and nursing homes. As the American Hospital Association pointed out in its amicus brief filed with the United States Supreme Court in the Cruzan case, approximately 2.2 million Americans die each year. Of the 1.3 million who die in hospitals, 70% die after a decision has been made to forego life-sustaining treatment.

So the choice is not whether individuals and their families, in collaboration with their physicians, will be making decisions about life-sustaining treatment -- they will -- but whether those involved will have the benefit of the statutory guidelines and procedural framework that A.16 and S.1211 would provide.

NJANPHA's Board of Trustees has endorsed these bills unanimously. Our unanimity is all the more impressive considering that NJANPHA's Board is comprised of 30 trustees representing virtually every major religious denomination in the State -- including Baptists, Catholics, Episcopalians, Jews, Lutherans, Methodists, Presbyterians and Quakers.

Contrary to the claim of those who oppose A.16 and S.1211, there is a broad and deep consensus among religious organizations -- and their health care facilities -- in support of these bills. Even our members who would not withhold or withdraw life-sustaining treatment at their own facilities support the right of other facilities to follow their institutional conscience. They also recognize that A.16 and S.1211 would establish the legal right of a religiously-affiliated facility to decline participation in withholding or withdrawing life-sustaining treatment by adopting an institutional conscience statement to that effect. Similarly, health care professionals would be permitted to decline on the basis of their personal beliefs.

PROPOSED AMENDMENTS

While we believe that these are good bills, we know they could be made better by amending the provisions concerning ethics committees, which are also referred to as "reviewing bodies." Our proposed amendments concern the process for resolving disputes among caregivers, residents, health care representatives and residents' families when there is disagreement about the resident's decision making capacity or interpretation of the resident's living will. In their present form, A.16 and S.1211 would require that the dispute be submitted to an "institutional or regional reviewing body" and would require that body to give advice about resolving the dispute.

The proposed amendments have two main thrusts. First, to change the reviewing body's function from giving advice to providing a consultation. Second, to make this process optional instead of mandatory. There is serious doubt whether, at this point in time, institutional ethics committees at hospitals and long-term care facilities are capable of giving definitive advice about a course of treatment for an active case (known as "prospective case review"). In fact, very few institutional ethics committees anywhere engage in prospective case review.

At this point in time, and for the foreseeable future, it is far more reasonable to expect from these committees a "consultation" (meaning an informed discussion), rather than a decision about a recommended course of action, which the word "advice" implies.

Each proposed amendment is explained in Attachment #1 and noted on Attachment #2, which contains the affected portions of S.1211.

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Attachment #1

PROPOSED AMENDMENTS TO S.1211

Section 14 **(Dispute Resolution); p. 12.** This section describes the process to be followed when the patient, the health care representative or the attending physician disagree about the patient's decision making capacity or interpretation of an advance directive. Subsection 14.a requires the parties to submit their dispute to a review committee.

The proposed amendments to Subsections 14.a and c would permit, but not require the parties to seek resolution of their disagreement through the facility's dispute resolution process. At all times, the parties would have the option of going to court.

Section 15 **(Decisions to Forego Life-Sustaining Treatment Other Than Fluids and Nutrition); pp. 12-13.** This section describes the circumstances under which a patient's directive to withhold or withdraw life-sustaining treatment (other than artificially provided fluids and nutrition) may be implemented. The fourth of these circumstances is:

> when the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the medical intervention to be withheld or withdrawn may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the medical intervention on an unwilling patient would be inhumane.

In such cases, Subsection 15.a would require the attending physician to seek consultation with an institutional or regional reviewing body or public agency before implementing the patient's directive to withhold or withdraw life-sustaining treatment.

The proposed amendment to Subsection 15.a would permit, but not require, the attending physician to consult with the institutional or regional reviewing body or public agency.

Section 16 **(Decisions to Forego Artificially Provided Fluids and Nutrition); pp. 13-14.** S.1211 makes a distinction between the withholding/withdrawing of fluids and nutrition and all other forms of life-sustaining treatment. In order to withhold or withdraw artificially provided fluids and nutrition, the patient must have specifically requested this in his or her living will. Section 16 concerns a patient's explicit directive to forego fluids and nutrition. The procedure parallels Section 15; the physician would be required to consult with an institutional or regional reviewing body or a public agency.

The proposed amendment to Subsection 16.a would permit, but not require, the attending physician to consult with an institutional or regional reviewing body or public agency.

Section 18 (Reviewing Bodies); pp. 14-15. This section describes the institutional and regional reviewing bodies which engage in prospective case review under Sections 15 and 16. In its current form, this section requires such bodies to give advice.

The proposed amendments to Subsection 18 have two purposes. First, they would change the reviewing bodies' function from giving advice to providing a consultation. Second, they would make the process optional rather than mandatory. The proposed amendments also would do away with the requirement that the reviewing bodies be accredited.

Section 22 (Immunity); p. 16. S.1211 would provide immunity to health care representatives and health care professionals when: (1) implementing the living will and (2) implementing the advice of an institutional or regional reviewing body. Since, under the earlier amendments, the function of the reviewing bodies would change from giving advice to providing a consultation, the reference to immunity when implementing the advice of a reviewing body would be deleted.

Section 27 (Regulations by the Ombudsman); p. 17. This section directs the Office of the Ombudsman for the Institutionalized Elderly to adopt regulations when the Act becomes law. The proposed amendment would clarify that the Office of the Ombudsman must conform its regulations to the Act.

Section 28 (Regulations by the Public Guardian); p. 17. For the same reasons stated in connection with the Ombudsman, the proposed amendment would require that the Public Guardian for Elderly Adults conform its regulations to the Act.

Section 29 (Failure to Follow Act); pp. 17-18. Subsection 29.a subjects a health care professional who "willfully" fails to follow the Act to discipline for professional misconduct. The proposed amendment would strike "willfully" and substitute the term "knowingly and purposefully."

Subsection 29.b provides that a health care institution that "willfully" fails to follow the Act shall be subject to a fine of not more than $1,000 for each offense. The proposed amendment would strike "willfully" and substitute the term "knowingly and purposefully."

and if a mutually satisfactory accommodation cannot be reached, shall take all reasonable steps to effect the appropriate, timely and respectful transfer of the patient to the care of another health care institution appropriate to the patient's needs, and shall assure that the patient is not abandoned or treated disrespectfully.

c. Nothing in this act shall be construed to require a health care institution to participate in the beginning, continuing, withholding or withdrawing of health care in a manner contrary to law or accepted medical standards.

14. a. In the event of disagreement among the patient, health care representative and attending physician concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive to the patient's course of treatment, the parties ~~shall~~ may seek to resolve the disagreement by means of procedures and practices established by the health care institution, including but not limited to, consultation with an institutional ethics committee, or with a person designated by the health care institution for this purpose~~.~~ or may seek resolution by a court of competent jurisdiction

b. A health care professional involved in the patient's care, other than the attending physician, or an administrator of a health care institution may also invoke the dispute resolution process established by the health care institution to seek to resolve a disagreement concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive.

~~c. If disagreement cannot be reconciled through an institutional dispute resolution process, the parties may seek resolution in a court of competent jurisdiction.~~

15. a. Consistent with the terms of an advance directive and the provisions of this act, life-sustaining treatment, other than artificially provided fluids and nutrition necessary to sustain life, may be withheld or withdrawn from a patient in the following circumstances:

(1) When the life-sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician;

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician; or

(4) In the event none of the above circumstances applies, when the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the medical intervention

to be withheld or withdrawn may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the medical intervention on an unwilling patient would be inhumane. In such cases prior to implementing a decision to withhold or withdraw life-sustaining treatment, the attending physician ~~shall promptly,~~ may seek consultation with an institutional or regional reviewing body in accordance with section 18 of this act, or ~~shall promptly~~ may seek approval of a public agency recognized by law for this purpose.

b. Nothing in this section shall be construed to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

c. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

16. a. Consistent with the explicit terms of an advance directive and the provisions of this act, artificially provided fluids and nutrition necessary to sustain life may be withheld or withdrawn from a patient in the following circumstances:

(1) When the artificial provision of fluids and nutrition is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician; or

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician, and the likely risks and burdens associated with the least burdensome treatment modality likely to be effective may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the intervention on an unwilling patient would be inhumane. In such cases, prior to implementing a decision to withhold or withdraw artificially provided fluids and nutrition, the attending physician ~~shall~~ may seek ~~prompt~~ consultation with a qualified institutional or regional reviewing body in accordance with section 18 of this act, or ~~shall promptly~~ may seek approval of a public agency recognized by law for this purpose.

b. Nothing in this act shall be construed to provide authorization for the health care representative, or any other individual acting pursuant to this act, to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to sustain life in the absence of explicit instructions to that effect in the patient's advance directive.

c. Nothing in this section shall be construed to impair the obligations of a physician, nurse or other health care professional to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

d. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

17. a. Consistent with the terms of an advance directive and the provisions of this act, the attending physician may issue a do not resuscitate order.

b. A do not resuscitate order shall be entered in writing in the patient's medical records prior to implementation of the order.

c. Nothing in this act shall be construed to impair any existing legal authority to issue a do not resuscitate order when the patient has not executed an advance directive.

→ (18.) a. An institutional or regional reviewing body which engages in prospective case consultation pursuant to paragraph (4) of subsection a. of section 15 and paragraph (3) of subsection a. of section 16 of this act ~~shall advise~~ may, upon request be consulted by the attending physician, patient ~~and~~ or health care representative, as to whether it believes that the withholding or withdrawal of the medical intervention under consideration would be in conformity with the requirements of this act, including without limitation: whether such action would be within the scope of the patient's advance directive; whether it may reasonably be judged that the likely risks and burdens associated with the medical intervention to be withheld or withdrawn outweigh its likely benefits; and whether it may reasonably be judged that imposition of the medical intervention on an unwilling patient would be inhumane. The attending physician, patient and health care representative shall also be advised of any other course of diagnosis or treatment recommended for consideration. ~~The advice of the~~ Consultation with an institutional or regional reviewing body shall be documented in the patient's medical records.

b. ~~The advice of~~ Consultation with an institutional or regional reviewing body ~~acting in accordance with subsection a. of this section~~ is not required. Furthermore nothing in this act shall be construed to impair the right of a ~~legally binding. A~~ health care representative, physician, nurse, or other health care professional who consults with an institutional or regional reviewing body ~~believes the advice should not be followed may choose~~ to:

~~(1) Pursue an alternative course of treatment for the patient. In this case, no immunity is conferred upon such actions by this act, and the individual is subject to existing norms of civil and criminal liability and may be subject to discipline by the respective State licensing board for professional misconduct.~~

~~(2)~~ (1) Seek review by a public agency recognized by law for this purpose: or

(1) ~~(3)~~ Seek review by a court of competent jurisdiction.

c. Nothing in this section shall preclude the transfer of the patient to another appropriate health care professional or health care institution. In this case the health care institution responsible for the patient's care shall assure that the health care professional or health care institution to which the patient is transferred is properly informed of the advice given by the institutional or regional reviewing body.

~~d. An institutional or regional reviewing body acting in accordance with subsection a. of this section shall conform to standards established by law and shall be subject to periodic accreditation and review under procedures established by law.~~

19. a. Nothing in this act shall be construed to alter, amend or revoke the rights and responsibilities under existing law of health care institutions not governed by the provisions of this act.

b. The provisions of this act shall not be construed to require emergency personnel, including paid or volunteer fire fighters; paramedics; members of an ambulance team, rescue squad, or mobile intensive care unit; or emergency room personnel of a licensed health care institution, to withhold or withdraw emergency care in circumstances which do not afford reasonable opportunity for careful review and evaluation of an advance directive without endangering the life of the patient.

20. In accordance with the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.) the Department of Health shall establish rules and regulations necessary to carry out the provisions of this act.

a. The department shall establish rules and regulations for the annual reporting by health care institutions, and the gathering of such additional data as is reasonably necessary to oversee and evaluate the implementation of this act. The department shall seek to minimize the burdens of record-keeping imposed by the rules and regulations and shall seek to assure the appropriate confidentiality of patient records.

b. The department shall establish rules and regulations requiring health care institutions to adopt policies and practices designed to:

(1) Make routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive;

(2) Provide appropriate informational materials concerning advance directives to all interested patients and their families and health care representatives, and to assist patients interested in discussing and executing an advance directive;

(3) Educate patients and their families and health care representatives about the availability, benefits and burdens of rehabilitative treatment, therapy and services, as appropriate;

(4) Inform physicians, nurses, and other health care professionals of their rights and responsibilities under this act, to assure that the rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this act; and

(5) Otherwise comply with the provisions of this act .

21. The Department of Health and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care established pursuant to P.L.1985, c.363 (C.52:9Y-1 et seq.), shall jointly evaluate the implementation of this act and report to the Governor and the Legislature, including recommendations for any changes deemed necessary, within five years from the effective date of this act.

22. a. A health care representative shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act:

(1) To carry out the terms of an advance directive; ~~or~~

~~(2) To follow and implement the advice of an institutional or~~ regional ~~reviewing body acting~~ in accordance with subsection a. ~~of section 18 of this act.~~

b. A health care professional shall not be subject to criminal or civil liability or to discipline by the health care institution or the respective State licensing board for professional misconduct for any actions performed in good faith and in accordance with the provisions of this act, any rules and regulations established by the Department of Health pursuant to this act, and accepted professional standards:

(1) To carry out the terms of an advance directive; ~~or~~

~~(2) To follow and implement the advice of an institutional or~~ regional ~~reviewing body acting~~ in accordance with subsection a. ~~of section 18 of this act.~~

c. A health care institution shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act to carry out the terms of an advance directive.

23. The absence of an advance directive shall create no presumption with respect to a patient's wishes regarding the provision, withholding or withdrawing of any form of health care. The provisions of this act do not apply to persons who have not executed an advance directive.

24. The execution of an advance directive pursuant to this act shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual because that individual has executed or has

not executed an advance directive. The execution, or non-execution, of an advance directive shall not be made a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program.

25. An advance directive executed under the laws of another state in compliance with the laws of that state or the State of New Jersey is validly executed for purposes of this act. An advance directive executed in a foreign country in compliance with the laws of that country or the State of New Jersey, and not contrary to the public policy of this State, is validly executed for purposes of this act.

26. a. The withholding or withdrawing of life-sustaining treatment pursuant to section 15 of this act or of artificially provided fluids and nutrition necessary to sustain life pursuant to section 16 of this act, when performed in good faith, and in accordance with the terms of an advance directive and the provisions of this act, shall not constitute homicide, suicide, assisted suicide, or active euthanasia.

b. To the extent any of the provisions of this act are inconsistent with P.L.1971, c.373 (C.46:2B-8 et seq.) concerning the designation of a health care representative, the provisions of this act shall have priority over those of P.L.1971, c.373 (C.46:2B-8 et seq.).

Durable powers of attorney for health care executed pursuant to P.L.1971, c.373 (C.46:2B-8 et seq.) prior to the effective date of this act shall have the same legal force and effect as if they had been executed in accordance with the provisions of this act.

c. Nothing in this act shall be construed to impair the rights of emancipated minors under existing law.

Conform its

→ ㉗ The Office of the Ombudsman for the Institutionalized Elderly shall ~~adopt~~ regulations ~~necessary~~ to ~~comply with~~ the requirements of P.L......, c....... (C........)(now pending before the Legislature as this bill), and shall make a written statement of its obligations under that act available to the public.

Conform its

→ ㉘ The Office of the Public Guardian for Elderly Adults shall ~~adopt~~ regulations ~~necessary~~ to ~~comply with~~ the requirements of P.L........, c........ (C...........)(now pending before the Legislature as this bill), and shall make a written statement of its obligations under that act available to the public.

→ ㉙ a. A health care professional who ~~willfully~~ fails to act in accordance with the requirements of this act is subject to discipline for professional misconduct pursuant to P.L.1978, c.73 (C.45:1-21).

Knowing and purposeful

b. A health care institution that ~~willfully~~ fails to act in accordance with the requirements of this act and regulations adopted in accordance with this act shall be subject to a fine of not more than $1,000 for each offense. For the purposes of this subsection, each violation shall constitute a separate offense.

Knowing and purposef

Penalties for violations of this act shall be recovered in a summary civil proceeding, brought in the name of the State in a court of competent jurisdiction pursuant to "the penalty enforcement law," N.J.S.2A:58-1 et seq.

c. The following acts constitute crimes:

(1) To willfully conceal, cancel, deface, obliterate or withhold personal knowledge of an advance directive or a modification or revocation thereof, without the declarant's consent, is a crime of the fourth degree.

(2) To falsify or forge an advance directive or a modification or revocation thereof of another individual is a crime of the fourth degree.

(3) To coerce or fraudulently induce the execution of an advance directive or a modification or revocation thereof is a crime of the fourth degree.

(4) To require or prohibit the execution of an advance directive or a modification or revocation thereof as a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program, or as a condition of the provision of health care is a crime of the fourth degree.

d. Commission of any of the acts identified in paragraphs (1), (2), or (3) of subsection c., resulting in the involuntary earlier death of a patient, shall constitute a crime of the fourth degree.

e. The sanctions provided in this section shall not be construed to repeal any sanctions applicable under other law.

30. This act shall take effect 180 days after the date of enactment.

STATEMENT

The "New Jersey Advance Directives for Health Care Act" is based on the recommendations of the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care. The major provisions of S-3320 are as follows:

1. Advance directives for health care may encompass both the designation of a health care representative ("a proxy directive") and/or a statement of personal wishes regarding health care in the event of loss of decision making capacity ("an instruction directive").

2. Advance directives may be revoked by oral or written destruction of the document or execution of a subsequent directive.

3. With regard to instruction directives, if a person chooses to instruct that artificially provided fluids and nutrition be withheld or withdrawn, that choice must be explicited stated in the directive.

4. An advance directive becomes operative when transmitted

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AMENDMENTS TO SENATE BILL NO. 1211
RESPECTFULLY SUBMITTED BY
THE NEW JERSEY HOSPITAL ASSOCIATION
AND
THE NEW JERSEY STATE BAR ASSOCIATION

Amend Section 4 to read as follows:

4. A declarant may execute an advance directive for health care at any time. The advance directive shall be signed and dated by, or at the direction of, the declarant in the presence of two subscribing adult witnesses, who shall attest that the declarant is of sound mind and free of duress and undue influence. A designated health care representative shall not act as a witness to the execution of an advance directive. Alternatively, the advance directive shall be signed and dated by, or at the direction of, the declarant and be acknowledged by the declarant before a notary public, attorney at law, or other person authorized to administer oaths. An advance directive may be supplemented by a video or audio tape recording.

Amend Section 14 to read as follows:

14. a. In the event of a disagreement among the patient, health care representative and attending physician concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive to the patient's course of treatment, the parties [shall] may seek to resolve the disagreement by means of procedures and practices established by the health care institution, including but not limited to, consultation with an institutional ethics committee, or with a person designated by the health care institution for this purpose or may seek resolution by a court of competent jurisdiction.

b. A health care professional involved in the patient's care, other than the attending physician, or an administrator of a health care institution may also invoke the dispute resolution process established by the health care institution to seek to resolve a disagreement concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive.

[c. If disagreement cannot be reconciled through an institutional dispute resolution process, the parties may seek resolution in a court of competent jurisdiction.]

Amend Section 15 to read as follows:

15. a. Consistent with the terms of an advance directive and the provisions of this act, life sustaining treatment [,other than] including artificially provided fluids and nutrition necessary to sustain life, may be withheld or withdrawn from a patient in the following circumstances:

(1) When the life sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician;

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician;

(4) In the event none of the above circumstances applies, when the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the medical intervention to be withheld or withdrawn may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the medical intervention on an unwilling patient would be inhumane. In such cases, prior to implementing a decision to withhold or withdraw life sustaining treatment, the attending physician [shall] may promptly seek consultation with an institutional or regional reviewing body in accordance with section [18] 17 of this act, or [shall] may promptly seek approval of a public agency recognized by law for this purpose.

b. Nothing in this section shall be construed to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with acceptable medical and nursing standards.

c. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

d. Nothing in this section shall be construed to provide authorization for the health care representative, or any other individual acting pursuant to this act, to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to sustain life in the absence of explicit instructions to that effect in the patient's advance directive.

Delete Section 16 in its entirety.

Renumber Section 17 as Section 16.

Amend Section 18 to read as follows:

[18.] 17. a. An institutional or regional reviewing body which engages in prospective case consultation pursuant to paragraph (4) of subsection a. of section 15 [and paragraph (3) of subsection a. of section 16] of this act [shall advise] and which is consulted by the attending physician, patient [and] or health care representative shall advise as to whether it believes that the withholding or withdrawal of the medical intervention under consideration would be in conformity with the requirements of this act, including without limitation: whether such action would be within the scope of the patient's advance directive; whether it may reasonably be judged that the likely risks and burdens associated with the medical intervention to be withheld or withdrawn outweigh its likely benefits; and whether it may reasonably be judged that imposition of the medical intervention on an unwilling patient would be inhumane. The attending physician, patient and health care representative shall also be advised of any other course of diagnosis or treatment recommended for consideration.

[The advice of] Consultation with an institutional or regional reviewing body shall be documented in the patient's medical records.

b. [The advice of] Consultation with an institutional or regional reviewing body acting in accordance with subsection a. of this section is not [legally binding] required. [A] Furthermore, nothing in this act shall be construed to impair the right of a health care representative, physician, nurse, or other health care professional who [believes that the advice should not be followed may choose to] consults with an institutional or regional reviewing body to:

[(1) Pursue an alternative course of treatment for the patient. In this case, no immunity is conferred upon such actions by this act, and the individual is subject to existing norms of civil and criminal liability and may be subject to discipline by the respective State licensing board for professional misconduct;

(2)] (1) Seek review by a public agency recognized by law for this purpose; or

[(3)] (2) Seek review by a court of competent jurisdiction.

c. Nothing in this section shall preclude the transfer of the patient to another appropriate health care professional or health care institution. In this case the health care institution responsible for the patient's care shall assure that the health care professional or health care institution to which the patient is transferred is properly informed of the advice given by the institutional or regional reviewing body.

[d. An institutional or regional reviewing body acting in accordance with subsection a. of this section shall conform to standards established by law and shall be subject to periodic accreditation and review under procedures established by law.]

Renumber Section 19 as Section 18.

Delete Section 20.

Renumber Section 21 as Section 19.

Renumber Section 22 as Section 20 and amend to read as follows:

[22.] 20. a. A health care representative shall not be subject to civil or criminal liability for any actions performed in good faith and in accordance with the provisions of this act [:

(1) To] to carry out the terms of an advance directive [; or

(2) To follow and implement the advice of an institutional or regional reviewing body acting in accordance with subsection a. of section 18 of this act].

b. A health care professional shall not be subject to civil or criminal liability or to discipline by the health care institution or the respective State licensing board for professional misconduct for any actions performed in good faith and in accordance with the provisions of this act [, any rules and regulations established by the Department of Health pursuant to this act,] and accepted professional standards [:

(1) To] to carry out the terms of an advance directive [; or

(2) To follow and implement the advice of an institutional or regional reviewing body acting in accordance with subsection a. of section 18 of this act].

c. A health care institution shall not be subject to civil or criminal liability for any actions performed in good faith and in accordance with the provisions of this act to carry out the terms of an advance directive.

Renumber Sections 23, 24, 25 and 26 as Sections 21, 22, 23 and 24, respectively.

Delete Sections 27 and 28.

Renumber Section 29 as Section 25 and amend to read as follows:

[29.] 25. a. A health care professional who [willfully] purposefully fails to act in accordance with the requirements of this act is subject to discipline for professional misconduct pursuant to P.L. 1978, c. 73 (C. 45:1-21).

b. A health care institution that [willfully] purposefully fails to act in accordance with the requirements of this act [and regulations adopted in accordance with this act] shall be subject to a fine of not more than $1,000 for each offense. For the purposes of this subsection, each violation shall constitute a separate offense. Penalties for violation of this act shall be recovered in a summary civil proceeding, brought in the name of the State in a court of competent jurisdiction pursuant to "the penalty enforcement law," N.J.S. 2A:58-1 et seq.

c. The following acts constitute crimes:

(1) To willfully conceal, cancel, deface, obliterate or withhold personal knowledge of an advance directive or a modification or revocation thereof, without the declarant's consent, is a crime of the fourth degree.

(2) To falsify or forge an advance directive or a modification or revocation thereof of another individual is a crime of the fourth degree.

(3) To coerce or fraudulently induce the execution of an advance directive or a modification or revocation thereof is a crime of the fourth degree.

(4) To require or prohibit the execution of an advance directive or a modification or revocation thereof as a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program, or as a condition of the provision of health care is a crime of the fourth degree.

d. Commission of any of the acts identified in paragraphs (1), (2), or (3) of subsection c., resulting in the involuntary earlier death of a patient, shall constitute a crime of the fourth degree.

e. The sanctions provided in this section shall not be construed to repeal any sanctions applicable under other law.

Renumber Section 30 as Section 26.

AMENDMENTS TO SENATE BILL NO. 1211
RESPECTFULLY SUBMITTED BY
THE NEW JERSEY HOSPITAL ASSOCIATION
AND
THE NEW JERSEY STATE BAR ASSOCIATION

Amend section 4 to read as follows:

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Amend section 14 to read as follows:

14. a. In the event of disagreement among the patient, health care representative and attending physician concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive to the patient's course of treatment, the parties [shall] may seek to resolve the disagreement by means of procedures and practices established by the health care institution, including but not limited to, consultation with an institutional ethics committee, or with a person designated by the health care institution for this purpose or may seek resolution by a court of competent jurisdiction.

b. A health care professional involved in the patient's care, other than the attending physician, or an administrator of a health care institution may also invoke the dispute resolution process established by the health care institution to seek to resolve a disagreement concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive.

[c. If disagreement cannot be reconciled through an institutional dispute resolution process, the parties may seek resolution in a court of competent jurisdiction.]

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Amend section 15 to read as follows:

15. a. Consistent with the terms of an advance directive and the provisions of this act, life-sustaining treatment [, other than] including artificially provided fluids and nutrition necessary to sustain life, may be withheld or withdrawn from a patient in the following circumstances:

(1) When the life-sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician;

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician; or

(4) In the event none of the above circumstances applies, when the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the medical intervention to be withheld or withdrawn may reasonably be judged to outweigh the likely benefits to the patient from such intervention, and imposition of the medical intervention on an unwilling patient would be inhumane. In such cases prior to implementing a decision to withhold or withdraw life-sustaining treatment, the attending physician [shall] may promptly seek consultation with an institutional or regional reviewing body in accordance with section [18] 17 of this act, or [shall] may promptly seek approval of a public agency recognized by law for this purpose.

b. Nothing in this section shall be construed to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

c. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment, based upon the free exercise of religion or the right of privacy, under either the United States Constitution or the Constitution of the State of New Jersey.

d. Nothing in this act shall be construed to provide authorization for the health care representative, or any other individual acting pursuant to this act, to direct or implement the withholding or withdrawal of artificially provided fluids and nutrition necessary to sustain life in the absence of explicit instructions to that effect in the patient's advance directive.

Delete section 16 in its entirety.

Renumber section 17 as section 16.

Amend section 18 to read as follows:

[18.] 17. a. An institutional or regional reviewing body which engages in prospective case consultation pursuant to paragraph (4) of subsection a. of section 15 [and paragraph (3) of subsection a. of section 16] of this act [shall advise] and which is consulted by the attending physician, patient [and] or health care representative shall advise as to whether it believes that the withholding or withdrawal of the medical intervention under consideration would be in conformity with the requirements of this act, including without limitation: whether such action would be within the scope of the patient's advance directive; whether it may reasonably be judged that the likely risks and burdens associated with the medical intervention to be withheld or withdrawn outweigh its likely benefits; and whether it may reasonably be judged that imposition of the medical intervention on an unwilling patient would be inhumane. The attending physician, patient and health care representative shall also be advised of any other course of diagnosis or treatment recommended for consideration.

[The advice of the] Consultation with an institutional or regional reviewing body shall be documented in the patient's medical records.

b. [The advice of] Consultation with an institutional or regional reviewing body acting in accordance with subsection a. of this section is not [legally binding] required. [A] Furthermore, nothing in this Act shall be construed to impair the right of a health care representative, physician, nurse, or other health care professional who [believes the advice should not be followed may choose to] consults with an institutional or regional reviewing body to:

[(1) Pursue an alternative course of treatment for the patient. In this case, no immunity is conferred upon such actions by this act, and the individual is subject to existing norms of civil and criminal liability and may be subject to discipline by the respective State licensing board for professional misconduct;

(2)] (1) Seek review by a public agency recognized by law for this purpose; or

[(3)] (2) Seek review by a court of competent jurisdiction.

c. Nothing in this section shall preclude the transfer of the patient to another appropriate health care professional or health care institution. In this case the health care institution responsible for the patient's care shall assure that the health care professional or health care institution to which the patient is transferred is properly informed of the advice given by the institutional or regional reviewing body.

[d. An institutional or regional reviewing body acting in accordance with subsection a. of this section shall conform to standards established by law and shall be subject to periodic accreditation and review under procedures established by law.]

Amendments to S-1211
NJHA/NJSBA
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Renumber Section 19 as Section 18.

Delete Section 20.

Renumber Section 21 as Section 20.

Renumber Section 22 as Section 21 and amend to read as follows:

[22.] 21. a. A health care representative shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act [:

(1) To] to carry out the terms of an advance directive [; or
(2) To follow and implement the advice of an institutional or regional reviewing body acting in accordance with subsection a, of section 18 of this act].

b. A health care professional shall not be subject to criminal or civil liability or to discipline by the health care institution or the respective State licensing board for professional misconduct for any actions performed in good faith and in accordance with the provisions of this act, any rules and regulations established by the Department of Health pursuant to this act, and accepted professional standards [:

(1) To] to carry out the terms of an advance directive [; or
(2) To follow and implement the advice of an institutional or regional reviewing body acting in accordance with subsection a of section 18 of this act].

c. A health care institution shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act to carry out the terms of an advance directive.

Renumber Sections 23, 24, 25 and 26 as Sections 22, 23, 24 and 25, respectively.

Delete Sections 27 and 28.

Renumber Section 29 as Section 26 and amend to read as follows:

[29.] 26. a. A health care professional who [willfully] purposefully fails to act in accordance with the requirements of this act is subject to discipline for professional misconduct pursuant to P.L. 1978, c. 73 (C.45:1-21).

b. A health care institution that [willfully] purposefully fails to act in accordance with the requirements of this act and regulations adopted in accordance with this act shall be subject

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to a fine of not more than $1,000 for each offense. For the purposes of this subsection, each violation shall constitute a separate offense. Penalties for violations of this act shall be recovered in a summary civil proceeding, brought in the name of the State in a court of competent jurisdiction pursuant to "the penalty enforcement law," N.J.S.2A:58-1 et seq.

c. The following acts constitute crimes:

(1) To willfully conceal, cancel, deface, obliterate or withhold personal knowledge of an advance directive or a modification or revocation thereof, without the declarant's consent, is a crime of the fourth degree.

(2) To falsify or forge an advance directive or a modification or revocation thereof of another individual is a crime of the fourth degree.

(3) To coerce or fraudulently induce the execution of an advance directive or a modification or revocation thereof is a crime of the fourth degree.

(4) To require or prohibit the execution of an advance directive or a modification or revocation thereof as a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program, or as a condition of the provision of health care is a crime of the fourth degree.

d. Commission of any of the acts identified in paragraphs (1), (2), or (3) of subsection c., resulting in the involuntary earlier death of a patient, shall constitute a crime of the fourth degree.

e. The sanctions provided in this section shall not be construed to repeal any sanctions applicable under other law.

Renumber section 30 as section 27.

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TESTIMONY

OF

JAMES T. HOLMES
GENERAL COUNSEL

ON

ASSEMBLY BILL NO. 16/SENATE BILL NO. 1211
THE NEW JERSEY ADVANCE DIRECTIVES FOR HEALTH CARE ACT
AND
ASSEMBLY BILL NO. 1413/SENATE BILL NO. 1208
THE NEW JERSEY DECLARATION OF DEATH ACT

BEFORE

THE ASSEMBLY JUDICIARY, LAW AND PUBLIC SAFETY COMMITTEE

NOVEMBER 15, 1990

Chairman Ford, I am Rob Holmes, General Counsel to the New Jersey Hospital Association which represents all of New Jersey's acute care hospitals and most of its specialty hospitals. In addition, many of our hospitals own or manage long term care facilities as part of their mission to provide a continuum of care for the residents of this state. NJHA would like to thank you for the opportunity to speak today on these most important issues of determination of death and living wills.

However, we would like to limit our comments to A-16/S-1211 and A-1413/S-1208, since the Hospital Association's Board of Trustees has taken a position only on those two bills. We have long supported the concept and need to codify New Jersey Supreme Court decisions regarding the termination of life supporting treatment, the recognition of the validity of living wills, and the prescribing of the means to execute such wills. The Association, in the absence of living will legislation has and will continue to advise its member hospitals that advance directives are relevant and useful evidence in attempting to interpret the wishes of incompetent patients. The Association has also long supported legislation which would enact the Uniform Determination of Death Act in New Jersey.

Our primary concern with A-16/S-1211, the "New Jersey Advance Directives for Health Care Act," is that it mandates the use of ethics committees as decision makers in certain, albeit limited, circumstances. The empirical research in this field as well as the anecdotal experience of members of hospital ethics committees in New Jersey, is clear on one point: if these committees are to be effective, they must not be forced to function as decision makers. They are most useful as consultative, educational bodies. Decision making should remain within the patient-family-physician triad.

To that end, we would recommend that language in section 15.a.4, mandating physician consultation with an ethics committee, be made permissive, that is, certain references to "shall" should be changed to "may." In addition, the consultative role of ethics committees should be made more clear in section 18 by using phrases such as "is consulted by" and "consultation with." Finally, we would ask that section 18.d be deleted. If institutional ethics committees are viewed as educational, consultative bodies and not as decision makers, we do not believe that it is necessary for them to "conform with standards established by law and be subject to periodic accreditation." One would be hard pressed to find two hospital ethics committees in New Jersey similar in function, membership, or internal procedures: some of our ethics committees engage solely in education, others perform prospective case consultation, while others are active in policy development; some are large, some very small, some include an attorney as a member, some specifically exclude attorneys; some have broad based community representation, some are largely composed of a single discipline from within the hospital; some keep detailed records of their meetings, some do not. Even with these distinctions, it would be difficult to argue that one ethics committee is more effective than another. If we have learned anything from our 15-year experience with hospital ethics committees, it is that they need the freedom to grow, to evolve, subject to their hospitals' mission and the needs of the community served. We believe that to subject these committees, many of which are in their infancy in New Jersey, to rigid legislative or regulatory standards is to ensure their ineffectiveness and ultimately their demise.

Secondly, we question the need to distinguish between artificially provided fluids and nutrition on the one hand and all other life sustaining treatment on the other. The New Jersey Supreme Court has repeatedly rejected any distinction between the termination of artificial feedings and the termination of other forms of life sustaining treatment. Accordingly, we would recommend that section 16 be deleted in its entirety and that section 15, which describes the circumstances under which life sustaining treatment may be withheld or withdrawn, be changed to include rather than exclude artificially provided fluids and nutrition.

Finally, we believe that sections 20, 27, and 28 mandating that the Department of Health, the Office of the Ombudsman for the Institutionalized Elderly and the Office of the Public Guardian for Elderly Adults adopt regulations to carry out the provisions of A-16/S-1211 are unnecessary and, in light of the specificity and detail contained in this bill, have the potential of causing duplication and confusion if not chaos.

In summary, while the New Jersey Hospital Association's Board of Trustees has taken a position of support for A-16/S-1211, that support is conditioned upon the incorporation of amendments addressing three areas of concern--ethics committees as decision makers, the distinction between artificially provided nutrition and hydration and other forms of artificial life support, and the requirement that three different agencies promulgate regulations to carry out the mandates of the bill.

As to A-1413/S-1208, the "New Jersey Declaration of Death Act," we believe that legislation is necessary to clarify the issue of the legality of brain death in New Jersey. Despite the New Jersey Supreme Court's decision in <u>Strachan v. JFK Memorial Hospital</u>, 209 N.J.Super. 300, A.2d 718 (1986), wherein it adopted Section one of the Uniform Determination of Death Act, many of our hospitals, their physicians, patients, and family members still express concern regarding the legality of brain death.

We are not opposed to those sections of this bill which would require the Department of Health and the Board of Medical Examiners to jointly adopt rules setting forth currently accepted medical standards to govern determinations of brain death. However, we recognize and are sensitive to the concerns of many physicians that legally mandating any particular test or procedure is unwise due to the rapidly changing nature of medical technology, that clinical evaluation of a patient is the most important step in determining the loss of brain function, and that determinations of brain death should be made according to "accepted medical standards."

We do oppose the religious exemption contained in sections 5 and 6. We are told by those physicians employed by our hospitals that clinical evaluation and confirmatory testing are the means by which death should be determined. To these physicians a patient is either clinically dead or is alive. They do not believe that religious or personal preferences should play a role in the determination of death. In addition, to require physicians or "other responsible persons" (presumably hospital employees) to determine whether a declaration of brain death would violate the "personal religious beliefs or moral convictions" of a particular patient would be especially burdensome from an administrative point of view. We also believe that such an intrusion would be viewed as less than compassionate by many of the families of those who do not object to brain death on religious grounds but nonetheless must be questioned as to their beliefs and moral convictions.

JTH:ph
11/15/90

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AARP

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SUMMARY OF AARP/VOTE* QUESTIONNAIRE

In August of 1989, AARP/VOTE sent a questionnaire on major issues to the New Jersey Assembly District candidates of the Democratic and Republican parties. The following is a summary of the responses of members of the General Assembly to the following question:

"Would you support an advance directive (living will) bill?"

Arthur A. Albohn (R)

I support legislation to this end.

Anthony J. Cimino (D)

I have not yet finished reviewing the specific provisions of the proposals pending before the Legislature. Therefore, I cannot commit to voting for any particular bill until my analysis is complete.

Harold L. Colburn, Jr. (R)

As I have already written to my constituents, I will support the present living will bill which passed the state Senate.

Jack Collins (R)

I support an individual's right to determine his/her health care needs and their ability to designate in a proxy who will be given legal authority to make health care decisions on their behalf should they become incompetent.

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* AARP/VOTE is the nonprofit, nonpartisan voter education fund of the American Association of Retired Persons designed to yield an electorate informed about matters of concern to older persons. It will not support or oppose candidates for office or any political party.

American Association of Retired Persons 1909 K Street, N.W., Washington, D.C. 20049 (202) 872-4700

Christopher Connors (R)

At some future point in time each of us or our family members are faced with the deeply personal decisions regarding medical care and treatment. Advanced directives for health care allow personal wishes to prevail and provide important guidance for health care professionals. There must be the utmost respect and protection for human dignity and the sanctity of life. The N. J. Bioethics Commission was established to provide comprehensive review and examination of the ethical and medical questions presented by modern science and technology.

John D'Amico (D)

I support S-3320 which would allow people of sound mind to make certain decisions, in advance, about how they wish to be cared for in the event of a terminal illness.

Alex DeCroce (R)

At this time I am inclined to vote in favor of legislation which would prohibit the removal of life-sustaining food, water, nourishment. I do support a person's right to make a directive outlining his or her personal wishes regarding other health care.

John Paul Doyle (D)

Yes.

Marlene L. Ford (D)

I support the living will legislation sponsored by Senator Ambrosio and currently before the legislature. My opponent, Assemblyman Singer, has voted in favor of legislation that would mandate medical treatment for terminally ill patients. I do not share his position, and I feel that the decision about what medical treatment to pursue should not be dictated by legislators, but rather decided by the patient and his or her family.

Thomas P. Foy (D)

I have not made a decision on this issue as of yet.

John A. Girgenti (D)

Yes.

Anthony Impreveduto (D)

I would support an advance directive (living will) bill.

Daniel P. Jacobson (D)

I would support an advance directive bill.

Barbara Faith Kalik (D)

I support the living will bill. In fact, I have written my own advance directive statement. I think everyone deserves to have their wishes respected and honored.

C. Richard Kamin (R)

As one of two members of the Bio Ethics Commission from the Assembly, I support the concept and intent of the advanced directive legislation.

Walter J. Kavanaugh (R)

No.

Edward H. Salmon (D)

I have not yet finished reviewing the specific provisions of the proposals pending before the legislature. Therefore, I cannot commit to voting for any particular bill until my analysis is completed.

Anthony S. Marsella (D)

Yes.

Robert J. Martin (R)

I have committed to support Senator Ambrosio's legislation, S-3320, feeling that a person has the right to make his/her own decision on such private, moral matters as Living Wills.

D. Bennet Mazur (D)

Yes. I support a living will that would allow elderly people to in advance sign a legal document directing the discontinuance of life support systems when they are terminally ill and comatose.

Jeffrey W. Moran (R)

At some future point in time each of us or our family members are faced with the deeply personal decisions regarding medical care and treatment. Advanced directives for health care allow personal wishes to prevail and provide important guidance for health care professionals. There must be the utmost respect and protection for human dignity and the sanctity of life. The N. J. Bioethics Commission was established to provide comprehensive review and examination of the ethical and medical questions presented by modern science and technology.

William J. Pascrell, Jr. (D)

Yes. I intend to support Sen. Ambrosio's bill.

Joseph D. Patero (D)

Unfortunately, I am as yet unprepared to comment on the living will question and specific proposals that are pending in the Legislature.

Frank M. Pelly (D)

I would have to review the provisions of the bills, prior to making a comment. However, I am sensitive to the concerns expressed by many of my older constituents on this extremely critical issue.

Elizabeth Randall (R)

I am the prime sponsor in the Assembly of the "Living Will" legislation which was recommended by the New Jersey Bioethics Committee. My legislation is identical to that which has been sponsored by Senator Ambrosio in the State Senate.

Joe Roberts (D)

I certainly support the development of a living will program in New Jersey so that individuals have the ability to make a determination about their continued reliance upon self-sustaining medical care. We need to provide individuals in New Jersey with the ability to make these difficult final decisions in the most dignified possible manner.

Patrick J. Roma (R)

I support the New Jersey Advance Directives for Health Care Act (S-3320). I have wrestled with my conscience regarding the controversial element of the bill containing a health care directive provision for removal of food and hydration if a person becomes incompetent. While I am personally in favor of the essence of human life, I also must respect and support a person's written directive for a block of food and water.

John E. Rooney (R)

With certain provisions such as NOT withholding food or water.

William P. Schuber (R)

Yes. I support an advance directive bill.

David C. Schwartz (D)

I fully support a "living will".

Robert C. Shinn, Jr. (R)

As I have already written to my constituents, I will support the present living will bill which passed the state Senate.

Bill Schluter (R)

I support the basic concept of an advance directive or "living will". The standards for these documents and the procedures which they allow should be very stringent. There should be rigid medical requirements under which such wills would become operative. Only certain people should be given authority to act under "living wills".

Robert G. Smith (D)

Yes.

George A. Spadoro (D)

I tend to support the concept of choice and personal decision, but I prefer to hear all of the debate on this issue before taking an absolute position on any of the bills involved.

Gary W. Stuhltrager (R)

Absolutely yes.

John A. Villapiano (D)

I support the concept of the Living Will bill. I feel that while they are in a responsible state, people should be allowed to make certain decisions that will affect their lives when they are no longer able to make these decisions for themselves.

Gerald Zecker (R)

Yes.

Citizens Concerned For Life — N.J., Inc.

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TESTIMONY BEFORE THE ASSEMBLY JUDICIARY COMMITTEE

PUBLIC HEARING - November 15, 1990

by

Rita Martin, Legislative Director, Citizens Concerned for Life-NJ

This Committee has before it today a panoply of bills dealing with issues at the end of life. Many are similar in nature. I will address my comments principally to S-1211, the Advanced Directives for Health Care Act, which seems to cover more intently all of the issues involved, and make a few comments on A-2467 because it addresses an additional aspect of the debate.

Citizens Concerned for Life- NJ recognizes the right of individuals to make decisions regarding their own health care, and we recognize the time and effort expended by the N.J. Bioethics Commission in preparing (this S-1211 proposal). Nevertheless, we feel the bill as written raises vexing moral problems, and lacks sufficient safeguards for some of our citizens.

Our principal concern is the provision allowing removal of treatment and fluids and nutrition from non-terminally ill patients.

S-1211 creates a class of patients termed "permanently unconscious", and includes in that class those patients in irreversible coma and persistent vegetative state. Both these conditions are difficult to diagnose with certainty. These patients, for the most part, are not terminally ill, do not have any underlying pathology thay will kill them, but are vulnerable simply because they are disabled. The bill creates a discrimination against a class of patients because they are in a state of dependency, denying them safeguards available to other patients, making them candidates for death by starvayion.

The bill adds, the definition of "permanently unconscious" is "without limitation", meaning other categories can be added. The circle of similarly vulnerable patients is very wide. Would those with Alzheimer's Disease be added? Would AIDS patients be added? Would those with mental retardation be added? Anyone who doesn't interact as people would like them to could become vulnerable to decisions to withhold basic care - not extraordinary or unusual care , basic care - solely because of permanent disability.

The bill also allows competent patients with a serious, eventually terminal,disease to opt for non-treatment and to refuse fluids and nutrition if they perceive the burdens of their illness to be too overwhelming. This seems to be legalizing suicide and assisted suicide. Patients in these circumstances should be offered information, counselling and support to help ease their burden, rather than offering them the right to cause their own death. The State does have a vested interest in preserving life, even impaired life.

Treatment withdrawal decisions should become applicable only when the patient is terminally ill, not before. Moreover, decisions to withold or withdraw artificially provided fluids and nutrition should not be permitted if doing so would in itself cause death, rather than death being caused by the underlying illness or injury.

S-1211 does not include an exception in cases of pregnancy. An Advanced Dorective should not be effective during the course of a pregnancy. A woman who has opted to continue her pregnancy, and is now in a critical medical condition would certainly want her baby protected if at all possible. A number of other states have included such clauses in similar legislation. We would like to see inserted a statement similar to Florida's Life-Prolonging Procedures Act which states an Advanced Directive shall have "no effect during the course of a pregnancy". We contend that most younger people who write "living wills", or advanced directives, assume they will become operative in the future when they are old. They do not consider what might happen should a critical condition arise"tomorrow". Therefore, should the unexpected happen, we also contend a pregnant mother would more than likely opt for treatment if it would save her baby's life.

S-1211 limits the right of institutions to refuse to participate in treatment removal decisions to only religiously affiliated institutions. This places an unfair burden on institutions and on staff of privately run corporations who have strong moral convictions against treatment withdrawal. Transferring a patient to another institution is not the answer, because the staff is still cooperating in the decision if this is done. And what if the patient refuses transfer? The right to refuse to participate in treatment withdrawal decisions should be extended to all institutions where staff and institutional policies conscientiously object to such participation. A requirement could be added that this policy be in writing and made known to patients before entering the institution. If this limitiation is allowed to remain in the bill, we may see the closing of some of our sorely needed nursing homes.

All life is precious. People should not be abandoned because they are dependent and disabled. Best efforts should be made to recognize the uniqueness of each petient, to keep them comfortable, to help them live with dignity until death takes them. We recognize the heartache and suffering of the families of patients with severe and long-term illnesses, but the pain of the family does not justify taking the life of the patient, nor should we allow the patient to take his own life.

# # # #

Regarding A-2467 which attempts to address situations where patients have not left written instructions, we feel the whole bill is hampered by the definition of terminally ill.
In this bill, terminally ill means having an incurable condition which will ultimately cause death and the application of life-sustaining treatment serves only to postpone the moment of death.
We submit this definition is far too vague because it can cover anyone from the patient on dialysis to the diabetic who must take insulin every day to survive. We also submit that the issue A-2467 addresses is very complicated and needs a great deal more study before legislation is attempted. It is premature and should not be released from committee.

Indeed, except for S-1208, and its companion A-1413, dealing with Neurological Determination of Death, we feel all the bills under discussion here are flawed and should not be released from committee. (Included with this testimony is our position paper on S-1208 which we do not oppose.)

8-3-90

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NEW JERSEY DECLARATION OF DEATH ACT (S-1208/A-1413)

The bill codifies existing New Jersey case law by providing a statutory basis for declaring death on the grounds of total and irreversible loss of all functions of the entire brain, including the brain stem (commonly known as "whole brain death"). In two important respects, the bill is unique among whole brain death laws currently in force by statute or court decision in 49 states across the country. First, the bill would mandate the adoption by law of uniform criteria for the determination of whole brain death, by requiring the Department of Health and the Board of Medical Examiners to adopt rules and regulations setting forth currently accepted medical standards, including criteria, tests and procedures, to govern such determinations. The bill requires that these standards be periodically reviewed and updated to keep pace with developments in medical technology. Second, the bill expresses an important commitment to respect for religious and moral values by recognizing the legal right of an individual to claim an exemption from the application of neurological criteria for determining death if such a declaration would violate that individual's personal religious beliefs or moral convictions. If adopted, New Jersey would be the first state to recognize such an exemption in its statutory law.

POSITION OF CITIZENS CONCERNED FOR LIFE-N.J. ON S1208/A1413

Brain Death is a medical reality. In dealing with brain death our primary concern must be to safeguard the patient from an incomplete or premature diagnosis. Any legal definition of death which allows a neurological determination is incomplete if it does not call for cessation of all functions of the brain, including the brain stem. Mandatory, consistent procedures for determining the death of the brain and brain stem must be followed to avoid premature diagnosis.

S-1208 defines neurological death as "irreversible cessation of all functions of the entire brain, including the brain stem", and calls on the Board of Health and the State Board of Medical Examiners to establish protocols for determining brain death. These protocols will be in the form of regulation so all New Jersey hospitals and physicians will be using the same standards. It also requires that the doctor making the diagnosis shall be "professionally qualified by speciality or expertise" to do so. It is not to be left to any physician, bust must be made by one experienced in the field.

Based on these provisions, Citizens Concerned for Life does not oppose S-1208.

We realize it is incumbent upon us, and all others with interest in the issue, to monitor the regulations which are to be proposed by the Department of Health and Board of Medical Examiners to be certain they are written in a way which best safeguards the patient.

The issue of brain death creates a moral difficulty for some of our citizens whose deeply held religious beliefs and traditions do not recognize neurological death. This is a unique situation. The accomodation made in S-1208 for freedom of religion should not negate the validity of the bill.

* * * * * * * * * * * * * * * * * * *

S1208 has passed the Senate, Assembly action is expected in early Fall.

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N.J. Right to Life 11/15/90

Patricia Coyle &

Medical Research Director

Marie Niemer

Legislative Director

A baby was declared "brain dead" in a Canadian hospital, and, because donation of his heart was being considered, he was transferred to a hospital in the United States. In the U.S. hospital he was tested and found to be alive. This was reported in the New England Journal of Medicine. (1)

Similar reports keep appearing in newspapers, including the following cases:

* Seattle Post-Intelligencer, 1-30-89. A Yakima,Wa. woman who doctors once said was in a state of "cerebral death" emerged from a deep, five-month coma 2 to 3 days after delivering her baby.
* The Modesto Bee (Ca.), 10-19-89. A few days after a doctor asked Jennifer Keough's parents to donate the teen-ager's organs, the girl scratched out a misspelled but coherent message, "I wat to tak to my mom." When her mother arrived at her hospital room in Hollywood, Florida, Jennifer waved and wrote notes to her. Because the respirator was connected, she could not speak.
* Kansas City Times, 2-13-75. A wink of the eye saved S. William Winogrond just as a surgeon was preparing to remove his kidneys and eyes. He is fully recovered.

When cases like these are reported, embarrassed physicians often dismiss them as "misdiagnoses". The case of Baby Luis Alvarado, (2) however, can not be swept away so easily. Although the public is constantly reassured about "death" based on brain criteria, the Alvarado case makes clear that something is terribly wrong.

Baby Luis Alvarado was born on September 6, 1989 in New York City. He looks like any other baby. He is fed and his weight gain is normal. He urinates and has bowel movements and needs diaper changes and bathing - just like any other baby. His blood pressure, body temperature, and skin color are all normal.

Despite all these signs of life in Baby Luis, a neurologist declared him "brain dead" two days after his birth. A week later the same neurologist retested him twice and again declared him "brain dead". Because of this diagnosis, the parents were told by the hospital that they must obtain a court order to continue treatment for the baby.

A court-appointed neurologist, Dr. Eviatar, testified on October 10, 1989 that she had tested Baby Luis, using the "guidelines provided by the Task Force for the determination of brain death in children", (3) that Baby Luis was comatose, that he had fulfilled these criteria, and was thus "brain dead".

On October 18, 1989 the court ruled that Baby Luis was dead and that life support could be removed. After appealing, the parents received permission from the court to have a doctor of their choice look at the baby. Their doctor said that the baby was definitely alive. The day after their doctor made that statement, the hospital, in defiance of court orders (the tests can be harmful), brought in another doctor, Dr. Peterson, to retest the baby. Based on Dr. Peterson's findings, the hospital reversed itself in court, stating that the baby was now not "brain dead".

This was not a case of error in the physician's testing. Luis Alvarado, a living baby, was pronounced dead because he met all the criteria of the Guidelines for the Determination of Brain Death in Children, **(3)** including being in a coma. These guidelines were presumably used with the 143 organ donors in 1988 who were less than 5 years of age and the 184 donors in 1989 of that age group. **(4)**

The Task Force which set up the Guidelines for Children provides a remarkable exercise in semantics. In its report, the Task Force begins by endorsing this statement: "An individual who has sustained ... irreversible cessation of all functions of the brain, including the brain stem, is dead". Then, illogically, the Task Force requires that the patient not have too low a temperature or blood pressure for age.

A child who is able to maintain a normal, or near normal, temperature or blood pressure cannot be "brain dead". The hypothalamus of the brain is the natural thermostat. The medulla of the brain controls blood pressure. In its Guidelines, therefore, the Task Force is insisting that the child must have some functions of the brain when the child is declared "brain dead" because of no function of the brain.

That illogical requirement was made "logical" by a feat of semantics. The Task Force simply defined what would be considered an "absence of brain stem function". Any function of the brain stem that had the bad luck not to be included in the definition of the Task Force could thenceforth be disregarded as a function of the brain.

The Task Force should not be completely blamed, however, for assuming that this nonsense would take wing. Who, for example, would quarrel with the success of the President's Commission for the Study of Ethical Problems in Medicine and Biological and Behavioral Research? In its 1981 report, Defining Death, (5) the Commission had urged the passage of a Uniform Determination of Death Act (UDDA). (6) The UDDA allows death to be pronounced when there is "...irreversible cessation of all functions of the brain, including the brain stem". The UDDA became law in many states. Comatose patients whom nobody would have dreamed of calling "dead" twenty years ago are now being declared legally dead in those states.

If the President's Commission had promoted a law that said that death could be declared when there is "...irreversible cessation of all functions of the eye, including the optic nerve", it would have been given short shrift. Everyone knows that non-functioning eyes are not equal to death. Most people have not objected to the UDDA's formula - "death equals non-functioning brain" - because hardly anyone knows enough about the brain to come up with a logical objection. That would include the medical profession. A 1989 survey of doctors and nurses who were likely to be involved in organ transplantation showed that 65% of them did not know the

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medical and legal criteria for "brain death". (7)

The new definition of death ("brain death") is based on a new philosophy which claims that certain comatose people may be regarded as dead. Objections have not been raised because most people do not yet realize that it <u>is</u> a philosophy. The public is under the false impression that doctors have scientific proof that a comatose patient with a non-functioning brain is dead. Some doctors wish to expand the new philosophy of death so that other categories of patients may be declared dead, for example, anencephalic babies, vegetative patients, Alzheimer's patients, etc. (8)

The idea of considering the comatose as dead was first presented in 1968, one year after the first successful human heart transplant, in the Journal of the American Medical Association. (9) This article, "A Definition of Irreversible Coma", was by the Ad Hoc Committee of the Harvard Medical School. The Committee presented no scientific data to justify translating "coma" into "death".

After the "Harvard criteria" were published by the Ad Hoc Committee, there was much discussion of the new philosophy of death in the medical literature. Shortly thereafter, several states passed laws allowing death to be declared using neurological criteria. This is perhaps an example of the frequently repeated dictum, "All social engineering is preceded by verbal engineering".

In 1974 Willard Gaylin wrote in Harper's Magazine, (10) "The problem [of euthanasia] is well on its way to being resolved by what must have seemed a relatively simple and ...ingenious method ... The difficult issues of euthanasia could be evaded by redefining death". Just a few years after Gaylin's statement, the UDDA became law in many states.

A patient may be declared legally dead according to the Uniform Determination of Death Act even though: the patient's heart is beating; he has circulation and respiration; he sweats and urinates; he has recordable blood pressure; the patient is turned to prevent bed sores; he is suctioned to prevent pneumonia, etc. **(11)** (No one, though, has explained how a corpse can get bed sores or pneumonia.)

In truth, from the patient's point of view, there is no need for a new definition of death. When a patient's brain has been grossly damaged, the patient dies very quickly. Only in the rarest of instances have such patients lived beyond a few days. Dr. David H. Ingvar states, "The mean period of continuing activity of the heart is only three to five days ... total brain death is not a prolonged state and of itself will never be a major medical or economic burden to society." **(12)**

Since such comatose patients die quickly despite the assistance of a ventilator, there is no substance to the claim of the President's Commission that modern technology has created a great need for a new definition of death. **(13)** It was because many legislators were convinced that there was such an urgent need that many states adopted the UDDA.

There are puzzling omissions in the recommendations of the President's Commission. In its report, it states, "The dead do not ...autoregulate..." (14) Autoregulation includes control by the brain of temperature, heart beat rate, hormone levels, salt and sugar levels, blood pressure, etc. These functions persist longer than other functions of the brain in comatose patients who are being assessed for "brain death". (15, 16) To avoid making false declarations of death, the testing of autoregulation would seem to be mandatory. Strangely, however, the Commission did not recommend that these functions be tested. (17)

The Commission presented a long list of caveats and tests of the brain. Its recommendations, however, were diluted enormously by the statement, "the 'functions of the entire brain' that are *relevant* to the diagnosis are those that are *clinically ascertainable*." (18) (Emphasis added.) The clinical tests which the Commission recommended are the following: (19)

* ice water in the patients' ears to see if their eyes move
* cotton touched to their eyes to see if they blink
* shining a light in their eyes to see if their pupils constrict
* twisting the patients' head to see their eye movements
* putting a tube down the trachea to see if they cough
* disconnecting the ventilator to see if they breathe on their own

The first five are tests of brain stem reflexes. Besides these reflexes, only one brain stem function was recommended for testing (disconnecting the ventilator). The Commission did not recommend that the jaw reflex and the snout reflex be tested although the Collaborative Study **(20)** had shown that those two reflexes were likely to persist longer than the reflexes that were recommended. **(21)** No reason was given for excluding the stapedial and other brain stem reflexes.

The Commission's recommendations are somewhat like the game of "let's pretend". Let's test a few reflexes and pretend that the whole brain can not function. Let's test for a few drugs and then pretend that there are no drugs involved. (It is virtually impossible to eliminate the presence of every drug by blood testing; there are thousands.) **(22)** Let's take the patient off the ventilator and pretend that he does not need the ventilator to counteract inadequate pulmonary function. (Patients with this condition can be harmed if taken off the ventilator. The condition has several causes, including trauma.) **(23)**

Unlike the children's game of "let's pretend", the Commission's recommendations create grave risks. That the Commission would countenance such hazards would suggest that they perhaps had a greater interest in producing a large pool of organ donors rather than in protecting criticallly-ill, comatose patients.

Medical experts testified to the Commission that the risk of mistake in a competently performed examination was "infinitesimal". **(24)** The medical experts were evidently wrong. If Bayesian probability theory were applied to the data that are presently available on "brain death" criteria, the theoretical risk of error "would hardly turn out to be negligible, let alone infinitesimal." **(25, 26)**

There are recent reports in the medical literature of patients who recovered fully after having met all the clinical criteria for "brain death". **(27, 28)** These recoveries would not have been predicted by the President's Commission, which stated that "the published criteria for determining cessation of brain functions have been uniformly successful". (29)

Continuing of brain function in those who are supposedly "brain dead" has been discussed in several medical journals. **(30 to 41)** Wetzel, et al, **(42)** observed some unusual reactions in a donor undergoing organ-removal. The records of nine other donors were then studied. In all ten cases, as soon as the scalpel cut into the body, the blood pressure and the heart beat rate rose dramatically. These changes should not have happened since the entire brain of these donors supposedly could not function. Such changes in pressure and heart beat rate occur in other patients undergoing surgery if they are not given enough anesthesia. Comatose organ donors are not given any anesthesia, although they are given muscle-paralyzing drugs to prevent movement during organ-removal.

The same reactions were seen in six "brain dead" donors by Conci, et al, who state, "The rises in heart rate and blood pressure were always related to the application of a specific surgical stimulus and vanished immediately after it was stopped." **(43)**

The largest study of "brain death", the Collaborative Study, **(20)** reported on 503 patients over a two-year period at nine prominent hospitals under the auspices of the National Institutes of Health. An autopsy was done on about half of the patients who died during the course of the study. In 60% of the cases destruction throughout the brain could not be found. **(44)** 43% of the patients who met the "Harvard criteria" did not have such brain destruction. **(45)** In 10% of the cases, no abnormality of the brain could be found by direct visualization or observation under the light microscope. **(46)**

None of the "brain death" criteria is based on data that are scientifically valid. The same is true of various tests which are supposedly "confirmatory" of "brain death" - these would include the EEG, the bolus blood-flow tests, ultrasound pulsations, PET scans, etc.

Not only have the clinical criteria for "brain death" never been shown to be valid, but, according to Bayesian probability theory, there is an inherent impossibility of validating them. **(26)** In light of this, some have suggested that angiography be used to test for "brain death". Angiography tests for blood flow to the entire brain. A dye is injected into the blood vessels and shortly thereafter the brain is X-rayed. Angiography can be toxic and may stop blood flow to the brain and could even cause death. **(47, 48)**

Giving such a dangerous test when all that need be done is to wait a few days , is not justified. If the patient's brain is grossly damaged, his/her heart will stop beating in a short time. **(12)** The angiogram would be given not for the patient's benefit, but rather for the benefit of those who need organs, those who wish to do research, or those who would benefit financially from the premature death of the patient.

A number of reports, moreover, show that brain function may continue although angiography indicates no blood flow to the brain. **(40, 41)**

Rabbi J. David Bleich points out that "There is no diagnostic method for determining when total lysis [liquifaction of the brain] has occurred, nor has total lysis ever been observed upon autopsy. Although the neurological causes are obscure, there is strong reason to believe that cardiac activity ceases long before total lysis could possibly occur." **(49)** In the Spring 1989 edition of Tradition, Rabbi Bleich presents an analysis of Jewish law demonstrating that a declaration of death based solely on brain criteria is not acceptable in the Jewish tradition. **(50)**

Those who embrace the philosophy that "brain death" is equal to death of the person frequently mention the fact that a heart can be removed from the body, and, if properly maintained, may continue to beat outside the body for a considerable period of time. Although this is true, it is not a valid argument. Most people are aware that people have lived with mechanical hearts for months. It is therefore not the organ of the heart that must be present and functioning, but rather the vital function of the circulatory system, which is part of maintaining the unity of the body.

Pope Pius XII made a clear statement in the following teaching: "But considerations of a general nature allow us to believe that human life continues for as long as its vital functions - distinguished from the simple life of organs - manifest themselves spontaneously or even with the help of artificial processes." **(51)** (Emphasis added.)

It would appear, according to Pius XII, that a patient deemed to be "brain dead" who is breathing with the help of a ventilator, is alive. Respiration is a vital function carried out only by someone who is alive. The ventilator (less properly called a respirator) moves air. A ventilator can cause air to move in and out of the chest of a corpse, but it can never cause a corpse to respire. In a corpse there can not be any respiration (exchange of oxygen and carbon dioxide).

The President's Commission viewed the brain as the primary organ or the regulator of the body's integrated functions. **(52)** The Commission theorized that a patient who does not exhibit certain brain functions has ceased to exist as an integrated entity. (53) From this philosophy regarding the brain, the Commission rationalized that certain comatose patients could be declared dead even though they show many signs of life.

The Commission deviated markedly from this philosophy when it made its recommendations for "brain death" testing. The Commission advocated as "relevant" the testing of five reflexes although these reflexes have no integrative function. (19) In contrast, brain functions that are integrative were not recommended for testing. (17)

The President's Commission is not alone in this respect. Omission of testing of integrative functions is virtually universal. Even the Harvard criteria for "brain death", which are supposedly "strict" criteria, omit the testing of the brain's autoregulatory functions. **(9)**

It is evident that, when the integrative functions are tested, very few patients can be declared "brain dead". This was made clear by the Collaborative Study's **(20)** assessment of the Japanese criteria for "brain death". **(54)** These criteria require an abrupt fall in blood pressure. (Control of blood pressure is one of the integrative functions of the brain.) Only 4% of the 503 patients in the Collaborative Study could be considered "brain dead" when an abrupt fall in pressure was required. **(55)** If the testing of other integrative functions of the brain had also been required, the percentage would undoubtedly have dipped below 4%.

Perhaps least understandable is the failure to require testing of the brain's control of the body's hormonal system (endocrine system). That omission is remarkable because the hormonal system itself regulates and integrates the body by means of hormones (chemicals released into the blood by

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glands). The hypothalamus of the brain greatly influences this hormonal system.

The hypothalamus may continue its integrating function even when there seems to be no blood circulation to the brain. Shrader, et al, reported that hormonal functioning continued in six patients although angiography indicated no blood flow to the brain. (56) They concluded that circulation "too small to be demonstrated by angiography, was maintained."

Professor R. M. Veatch asks, "When should persons be considered dead, that is, when should they be considered to have lost whatever it is that makes them an integrated entity...?" (57) He immediately notes, "It should be clear that no amount of science can answer such a question. It is <u>not</u> a scientific question." (Emphasis added.)

Byrne, et al, reject the idea that the brain is the sole integrating center for the vital functions of the body. (58) The body's functioning, they state, involves a complex interaction of at least three vital systems - the circulatory system, the respiratory system, and the brain. According to Byrne, et al, to assert that the brain is <u>the</u> integrating center "is to elevate the brain to a status which it does not really have, making it the sole principle of human life and reducing the body's other integrating systems to mere collections of organs. Such an approach virtually equates the brain with the human soul." (59)

Recent research indicates that the brain is not the sole integrating center. (60,61) When thyroid and steroid hormones were given to "brain dead" patients, heart function and metabolism improved. Survival was prolonged by this improvement to the extent that surgery for organ-removal could be more conveniently scheduled. (62) This utilization of hormones so as to extend survival is a complex process which requires bodily integration. Thus, these so called "brain dead" patients evidently have integration. (63)

Professor Josef M. Seifert notes that during the development of the embryo the brain makes a late appearance and for this reason the brain may not be regarded as the center of unity of the organic life of the organism. (64) Seifert further states, "As long as some growth, nutrition, regeneration, body temperature and maintenance of the live body through the circulation of oxygen, circulatory and organ activity (albeit externally supported) occur, the essential self-engendering character of life is preserved and the life of the organism as a whole can hardly be denied. In an actually dead man none of these things will happen, however many machines we use on him. As long as some vital functions such as the process of nutrition and circulation of the 'body as a whole' are preserved, even if one or another organ is not functioning, the life of the human organism as a whole cannot be justifiably denied." (65)

Another school of thought about "brain death" focuses on consciousness rather than on the integrative functions. This philosophy regards irreversible unconsciousness as equivalent

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to death. Sir John Eccles, who holds this view, conceives of the human soul as linked through certain areas of the brain necessary for consciousness. (66,) If this link is broken, the person may be considered to be dead, even though the rest of the body is alive. This view of the human soul would appear to conflict with Roman Catholicism since in the year 1312 the Council of Vienne declared that it is heretical to hold that the soul is not a form of the entire body. (67)

In 1985 Dr. D. Alan Shewmon argued from the principles of Thomas Aquinas that Alzheimer's patients and others without consciousness may be considered dead.(68) He has since abandoned that position for one which conceives of the brain as <u>the</u> integrator of the body.(69) Seifert states that Shewmon's former position contradicts Aquinas' thesis of the unicity of the soul of man and that "...it would be wholly impossible for Thomas that a human body after ensoulment, as long as it possesses sensitive and biological life, could be 'deserted by his rational soul'." (70) Seifert also states that "as long as a man as a whole is alive biologically, he must not be declared dead as a person. To do so would give rise to an unbearable 'dualism' which would jeopardize the substantial unity of man and of the human person. The very notion of 'brain death' implies a strong dualism between personal and biological life." (71)

Pope John Paul II recently cautioned the conference on determining the moment of death sponsored by the Pontifical Academy of Sciences as follows: "...there is a real possibility that the life whose continuation is made unsustainable by the removal of a vital organ may be that of a living person, whereas the respect due to human life absolutely prohibits the direct and positive sacrifice of that life, even though it may be for the benefit of another human being who might be felt to be entitled to preference ...Scientists [must determine] the exact moment and indisputable sign of death." (72) (Emphasis added.)

The case of baby Luis Alvarado, the observations of Rabbi Bleich mentioned herein, and the total absence of validated "brain death" criteria, all these point to a situation of serious doubt. Science, therefore, is not able to provide a basis for objective moral certitude that "brain death" is equivalent to personal death. Subjective moral certitude is not sufficient in a matter so serious as the pronouncement of death. (73)

When there is doubt about life or death, the question must be settled in favor of life. Lutherans, for example, denounce any effort "forcibly to interrupt the movement of man's spirit as it may be communicating through God's Spirit with His Creator and Redeemer by way of responding in trust and inner yearning" during the time just prior to death.(74)

"If death," states Seifert, "by its own objective essence as human death, is constituted by the soul leaving the body, if it consists in the mystery of the end of that union of life, soul, and body which constitutes personal human life, then it becomes quite impossible and ludicrous to identify, in terms of various brain death criteria of external and philosophically irrelevant nature, an exact moment of death in a human being who is alive biologically." **(75)**

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New Jersey Organ And
Tissue Sharing Network

November 15, 1990

Assemblywoman Ford, Chairperson
Assembly Judiciary, Law and Public Safety Committee

The New Jersey Organ And Tissue Sharing Network, along with the Medical Society of NJ, NJ Hospital Association, NJ State Bar Association and the NJ State Nurses Association, opposes the passage of Assembly Bill No. A-1413, known as the New Jersey Declaration of Death Act.

The intent of this Act is to legally define death by statute. While New Jersey needs a Declaration of Death Act, there are many problems associated with the proposed legislation.

If A-1413 were to pass the Legislature and be signed by the Governor, the Network's ability to recover organs would be seriously impaired. New Jersey's rate of organ recovery per million population is currently one of the lowest in the country.

Sections 5 and 6 of the Bill cause the greatest problem for the Network. These sections would restrain a physician from declaring death based on neurological criteria, if that diagnosis is contrary to the patient's religious or moral convictions.

All organ donors must be declared brain dead before solid organs can be recovered for transplantation. This Bill allows for individuals outside the medical community to override a medical diagnosis which is based on scientific findings. That would not only burden the family with making the diagnosis of death, but would strain already scarce health care resources and add significant costs to the health care system. With advancing sophistication in medical technology and care, the ability to sustain the bodily functions of a brain dead individual will markedly increase.

150 Morris Avenue Springfield, NJ 07081 Telephone (201) 379-4535 1-800-541-0075 Fax: (201) 379-5113

Additionally, this proposed legislation is not consistent with the Uniform Definition of Death Act as proposed by the Uniform Law Commission and adopted by forty-four other states. We believe that the current wording will create more problems than the bill would solve and may lead to confusion, law suits, unnecessary use of already critically scarce and expensive health care resources and a decline in life saving organ recovery.

I respectfully request that the Committee oppose A-1413 in it's current form.

Respectfully submitted,

Denise A. Payne, RN, MPA
Executive Director

11/15/90
A-1413 & S-1208

TO: Assemblywoman Ford, Chairwoman, and
Members of The Assembly Judiciary Committee

FROM: PAUL A. BYRNE, M.D.

1. I am Paul A. Byrne, a Doctor of Medicine. I graduated from St. Louis University School of Medicine in 1957 and have been actively practicing and teaching since that time. I am certified by the American Board of Pediatrics and the Sub-Board of Neonatal-Perinatal Medicine. I have been studying brain death for more than 15 years and have authored or co-authored articles in the medical literature, including the Journal of the American Medical Association, and the law literature, including an in-depth article entitled "The Patient, the Physician and Society".

2. I am opposed to Senate Bill 1208. This Bill makes different easily distinguishable, clinical situations, i.e., either cessation of circulatory and respiratory functions, or cessation of functions of the entire brain, identical and equivalent. This is contrary to the biological facts and must not be incorporated into law.

3. This law requires in Section 4.a., that a declaration of death upon the basis of neurological criteria be made "... by a licensed physician professionally qualified by specialty or expertise...", but then in Section 6a., such a declaration can be made by "...or another responsible person designated for that purpose...". This is contradictory to the requirement in Section 4.a.

4. This law provides that "... [a] licensed healthcare practitioner, hospital, or the healthcare provider... shall not be subject to criminal or civil liability or to discipline for unprofessional conduct with respect to those actions." Why would anyone give physicians or anyone else immunity in a matter so important as the pronouncement of death? If the pronouncement of death based on neurological criteria becomes the signal to cut out the beating heart, after the heart is removed, the question of death and liability from such action is moot from the dead patient's point of view, because now the patient is clearly dead. It does not seem prudent to grant this immunity to those involved.

5. Already, by 1978 there were more than 30 sets of brain related criteria for death published in the medical literature, and since that time, there have been many others. A patient on a ventilator, can be determined to have irreversible cessation of the functions of the entire brain, in the opinion of a neurologist or multiple neurologists. Such a patient has a beating heart, a recordable blood pressure, and a normal temperature, as well as many other organs and systems of the body are intact and functioning. The determination is made by

observing absence of certain tested brain functions when it is not known whether or not the brain has been destroyed. The declaration then becomes the signal to remove the still beating heart for transplantation. After which, the patient is clearly dead.

6. This law calls for "...irreversible cessation of all functions of the entire brain, including the brain stem." One would presume that there would be cessation of all the functions of the brain stem, when in fact, the only functions of the brain stem that are even evaluated are the brain stem centers for breathing, and the brain stem reflexes. The other functions of the brain stem including control of temperature, blood pressure, and heart rate, as well as the hormonal controls that originate from the hypothalmic-pituitary areas to the thyroid and adrenal glands are intact and required to be functioning at the time of a declaration of death.

7. This law results in more than one concept of death, determined by more than 30 different sets of criteria, becoming identical and equivalent. Thus, there are at least 32 ways to be dead by this law. This is contrary to the biological facts. The declaration of death must not be further abused with legislation, such as Senate Bill 1208. Legislators represent all the people, even those unresponsive and comatose, and perhaps dying. These constituents must also be represented, as well as the physicians and others given immunity by this law. When there is a question of doubt as to whether or not a patient is dead, the doubt must not be resolved by calling the patient dead, and then excising the beating heart. Great care must be taken not to declare a person dead, even a moment before death has actually occurred.

Respectfully,

Paul A. Byrne MD
Paul A. Byrne, M.D.

PAB/bh

Brain death — still a controversy

Joseph C. Evers, M.D., and Paul A. Byrne, M.D.

Dr. Evers, (ΑΩΑ, Georgetown University School of Medicine, 1954) is associate clinical professor of pediatrics at his alma mater, and is in the private practice of pediatrics in McLean, Virginia. Dr. Byrne graduated from the St. Louis University Medical School in 1957 and has served on the faculties of his alma mater, Creighton University Medical School, and Oral Roberts University Medical School. Since 1989, he has been chairman of the Department of Pediatrics, St. Vincent's Medical Center, Bridgeport, Connecticut.

The question of "brain death," or, more accurately stated, brain-related criteria for death, revolves around whether or not someone determined to have fulfilled a set of criteria is, in fact, dead. One of the questions this article addresses is whether the medical profession, in establishing brain-related criteria for death, has pinpointed the moment of death and whether any doubt exists as to the conclusion of personal death. It is our contention that the present state of the art has in fact failed to pinpoint the moment of death, and that insoluble doubt exists as to whether the patient on a ventilator declared "brain dead" is truly dead or rather is dying and is, therefore, still alive.

It is further our contention, that irreversible cessation of all functions of the entire brain is not necessarily equivalent to destruction of the entire brain. Even if it were possible, using present-day criteria, to determine destruction of the entire brain in each and every instance, we would need to ask, Is this state equivalent to death of the person?

Because one of the reasons for determining death based on brain-related criteria is to allow organ removal and transplantation, it is imperative from the moral point of view to be able to determine beyond any doubt that the person from whom vital organs are to be removed is truly dead, for someone who is not dead before vital organ removal will surely be dead after their removal.

At a 1987 bioethics conference in Melbourne, it was stated:

> [T]he traditional criteria of clinical death, namely the cessation of respiration and heart-beat, with the consequent destruction of the brain and all organs, recognized that as long as the oxygen transmission and blood-circulation are, by artificial means or spontaneously, intact, life of the organism as a whole, with its essential marks, is present.[1]

With the advent of medical technology and the emergence of organ transplantation, the "traditional criteria" were challenged and new criteria for death were established. It was the report of the Ad Hoc Committee of the Harvard Medical School that brought to the medical community's attention the concept of brain death. It addressed the problem of irreversible coma and in defining this entity offered criteria for its recognition. The Harvard criteria, as they are now known, were published in the *Journal of the American Medical Association (JAMA)*, in 1968 under the title, "A Definition of Irreversible Coma," but in the article "coma" was translated into "brain death."[2] Many in the medical and legal community now accept brain death as being identical to death of the person. In a recent survey of physicians and nurses likely to be involved in organ procurement for transplantation, however, only 35 percent, understood the medical and legal concepts of brain death.[3]

Most states in the United States presently have brain-death statutes. Because of the lack of uniformity in these statutes, however, in 1980 the National Conference of Commissioners on Uniform State Laws, in collaboration with the American Bar Association and the American Medical Association, formulated the Uniform Determination of Death Act (UDDA).[4] It states:

> An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire or
> including the brain stem, is d
> A determination of death mus
> made in accordance with
> cepted medical standards.[4, p.

Many states have adopted thi
a statute.

Confusion exists in the litera
over the terms "cessation of br
function" and "brain destructi
During sleep there is loss of s
brain functions, which upon av
ening are recovered. Narcotics
toxins result in cessation of m
brain functions, which with pr
medical management are c
pletely reversible. What we mea
"brain destruction" must be c
fied. One of us (P.A.B.) previo
suggested that in this context,
use the word *destroy* in its prim
sense: "to break down or disi
grate the basic structure of," "to
rupt or obliterate the constitutive
ordered unity of."[5] Nor should "
struction" imply abruptness of p
ical violence. "For the brain, '
struction' implies such damage to
neurons that they disintegrate p
ically both individually and col
tively."[5]

The Collaborative Study of Br
Death by the National Institute
Neurological and Communicat
Disorders and Stroke,[6] as descri
by the Committee for Pro-Life Ac
ities of the National Conference
Catholic Bishops in their "Resou
Paper on Definition of Death Le
lation,"[7] hoped to prove that c
sation of brain function coinci
with brain destruction, also cal
"respirator" brain. The study
cluded 503 patients in unrespons
coma and apnea. Of the total stu
in which 44 patients did not die,
brain specimens were examined
cellular pathology. At autopsy "a
of the specimens . . . showed n
of the pathological evidence of
pirator brain despite electrocere
silence up to the moment of sp
taneous cardiac arrest."[6, p. 13
fact, no more than 40 percent of
the brains analyzed were diagno
as respirator brains, [and] .
[n]either the Harvard criteria nor

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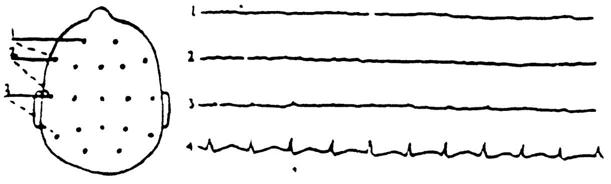
other widely used brain death criteria were found to correlate consistently with evidence of brain destruction."[7, p. 45] Gaetano F. Molinari (George Washington University Medical Center), project officer of the study, called this "one of the major and most disturbing findings."[8, p. 63] A larger clinical study was recommended, but to date, this has not been done.[9]

In determining brain death, both the UDDA and the Guidelines for The Determination of Brain Death in Children call for "irreversible cessation of all functions of the entire brain, including the brain stem."[4, 10] Absence of brainstem function is defined by lack of response to testing of some brainstem reflexes. Temperature control, blood pressure, salt and water balance, and cardiac rate, also functions of the brainstem, do not have to be considered in determining "brain death." There is, further, in the Guidelines for . . . Children a requirement that "[t]he patient must not be significantly hypothermic or hypotensive for age."[10] If the patient is neither hypothermic nor hypotensive and a warming device and cardiopressor drugs are not in use, then the brainstem not only still has functions, but also is functioning.

Laboratory tests that are considered confirmatory of brain death have intrinsic limitations. Electroencephalography evaluates electrical activity from only the surface of the brain. Patients who have had an isoelectric recording have been known to recover.[11] Evaluation of absence of cerebral circulation to the whole brain by means of four-vessel angiography is limited in use because of the potential of vasospasm actually causing no circulation to the brain. Also, "the bolus technique does not evaluate for critical deficit of blood flow through the whole brain, only the supratentorial part."[12]



Assuming that all the "brain-death" criteria have been fulfilled, how is it that a patient determined to have "irreversible cessation of all functions of the entire brain, including the brain stem,"[4] can be maintained by life-support systems just so long, and then the integrating systems fail and the person dies? While being maintained, many systems are interdependently functioning, including the cardiovascular system, the exocrine and endocrine systems, the excretory system, and the digestive system. In other words, body function and unity still exist.[13] This unity continues for a period of days, even weeks; then inevitably all systems fail and "somatic" death occurs.

Norman Fost wrote in a commentary in the *Journal of Pediatrics* in 1980:

> Other experiences and intuitions suggest that death of the brain is not the same as *death* in the traditional sense. . . . Brain death appears to be a critical juncture in the complicated process which constitutes death of the organism, but by itself it is not equal to death.[14]

In 1982 the *JAMA* reported the case of a twenty-four-year-old woman, twenty-three weeks pregnant, who was admitted to the hospital in status epilepticus. She was declared brain dead on the nineteenth hospital day and was maintained on a life-support system for a period of five more days, at which time she could no longer be kept alive. At the bedside a "vigorous" twenty-nine-week gestational age baby was delivered by cesarean section.[15]

Commenting on this and another case, Mark Siegler and Daniel Wikler wrote:

> Now we are told that a brain-dead patient can nurture a child in the womb, which permits live birth several weeks "postmortem." Perhaps this is the straw that breaks the conceptual camel's back. It becomes irresistible to speak of brain-dead patients being "somatically alive" (what sort of "nonsomatic death" is the implied alternative?), of being "terminally ill," and eventually, of "dying." These are different ways of saying that such patients (or, at least, their bodies) are alive. The death of the brain seems not to serve as a boundary; it is a tragic, ultimately fatal loss, but not death itself. Bodily death occurs later, when integrated functioning ceases.[16]

We ask: Is there a corpse on the machine, or is there a still-living, albeit "brain-dead" person on the machine? If it is a corpse, would you not have to refer to it at the very least as a "dying corpse?" Like a square circle, this is a contradiction in terms. You can have one or the other, not both. If the declaration of "brain death" becomes the signal to excise the still-beating heart, the patient becomes certainly and beyond doubt dead.

If one is so positive that all "brain death" criteria determine "brain death," why is it, we ask, so necessary to have so many different sets of criteria? More than thirty different sets of "brain death" criteria had already been reported by 1978.[17] Some require an electroencephalogram; some do not. For example, the Minnesota criteria do not require an electroencephalogram, while the Harvard, Japanese, and Collaborative Study criteria do. In Europe, things are different: England, like Minnesota, does not require an electroencephalogram; in Norway an arteriogram is required. Thus, a patient in one locality could be determined to be dead by one set, but not dead in another locality using another set.

In addition, we ask, How scientifically valid are the criteria? The UDDA relies upon the existence of "accepted medical standards" for determining that death has occurred.

AMENDMENTS TO SENATE BILL NO. 1211
RESPECTFULLY SUBMITTED BY
THE NEW JERSEY HOSPITAL ASSOCIATION
AND
THE NEW JERSEY STATE BAR ASSOCIATION

Amend section 4 to read as follows:

4. A declarant may execute an advance directive for health care at any time. The advance directive shall be signed and dated by, or at the direction of, the declarant in the presence of two subscribing adult witnesses, who shall attest that the declarant is of sound mind and free of duress and undue influence. A designated health care representative shall not act as a witness to the execution of an advance directive. Alternatively, the advance directive shall be signed and dated by, or at the direction of, the declarant and be acknowledged by the declarant before a notary public, attorney at law or other person authorized to administer oaths. An advance directive may be supplemented by a video or audio tape recording.

Amend section 14 to read as follows:

14. a. In the event of disagreement among the patient, health care representative and attending physician concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive to the patient's course of treatment, the parties [shall] may seek to resolve the disagreement by means of procedures and practices established by the health care institution, including but not limited to, consultation with an institutional ethics committee, or with a person designated by the health care institution for this purpose or may seek resolution by a court of competent jurisdiction.

b. A health care professional involved in the patient's care, other than the attending physician, or an administrator of a health care institution may also invoke the dispute resolution process established by the health care institution to seek to resolve a disagreement concerning the patient's decision making capacity or the appropriate interpretation and application of the terms of an advance directive.

[c. If disagreement cannot be reconciled through an institutional dispute resolution process, the parties may seek resolution in a court of competent jurisdiction.]

The report "Defining Death," by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, states: "The medical profession, based upon carefully conducted research and extensive clinical experience, has found that death can be reliably determined by either cardiopulmonary or neurologic criteria."[18, p. 161] the Harvard criteria were published without patient data. The Minnesota criteria resulted in elimination of electroencephalographic evaluation in a determination of death after doing electroencephalogram recordings on only nine patients, two of whom still had electroencephalographic activity when they were determined to be dead. A. Earl Walker, commenting on this said that "8% of patients would be classified as cerebrally dead in the presence of biological activity in the EEG — certainly an anomalous and undesirable situation."[19] Elsewhere, Dr. Walker wrote: "Based upon the findings of the Collaborative Study, from *8% to 40%* of persons [our emphasis] meeting different sets of clinical criteria for brain death had biological activity in their electroencephalograms."[20] Furthermore, the Collaborative Study found at autopsy that 10 percent of persons had no evidence of pathology of the brain. Do these reports reflect "carefully conducted research and extensive clinical experience . . . that death can be reliably determined by either cardiopulmonary or neurologic criteria"?[18, p. 161] We think not.

No matter how seemingly rigid the criteria are, the ease with which they can be bent is manifested in the report by the President's Commission.

> An individual with irreversible cessation of all functions of the entire brain, including the brainstem, is dead. The "functions of the entire brain" that are relevant to the diagnosis are those that are clinically ascertainable.[18, p. 162]

In one sentence, whatever stringency there was has been reduced to no more than what is "clinically ascertainable."

A human being belongs to the species *Homo sapiens* and, as such, is a person throughout his entire life, still when dying. There are attributes of a living human being that do not belong to other species, for example, thinking, judging, loving, willing, and acting. When it is predicted that a particular living human being will not be capable of demonstrating these attributes again, this living human being does not then belong to another species. He is still a living human being, a living person. To say that a patient on a ventilator, declared "brain dead," is certain to die and is, therefore, no longer a person, is to deny reality.

Great care must be taken not to declare a person dead even one moment before death has actually occurred. Death should only be declared after, not before, the fact, as to declare death prematurely is to commit a fundamental injustice. A person who is dying is still alive, even a moment before death, and must be treated as such.

In conclusion, we believe that destruction of the entire brain can occur, but that criteria to determine this state reliably have not been established. Cessation of brain function is not the same as destruction. In the present state of the art of medicine, a patient with destruction of the entire brain is, at the most, mortally wounded, but not yet dead. Death ought not be declared unless and until there is destruction of the entire brain, and of the respiratory and circulatory systems as well.

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November 12, 1990

Assemblywoman Marlene Lynch Ford
200 Main Street
Suite Z
Toms River, New Jersey 08753

RE: SENATE BILL No. 1211
"NEW JERSEY ADVANCE DIRECTIVE FOR HEALTH CARE ACT"

VIA FAX AND FEDERAL EXPRESS

Dear Assemblywoman Ford:

I am pleased to present my credentials and an article I have authored regarding Senate Bill No. 1211, "New Jersey Advance Directive for Health Care Act". Please submit this article as my testimony to be presented at the Assembly Judiciary Committee Hearing scheduled for Thursday, November 15, 1990. Regretfully, I am unable to attend the hearing. Please note that I have several serious concerns with this bill in its current form but believe these can be alleviated through further amendments. The proposed bill will be very difficult to implement and will cause increased rather than reduced litigation.

Please feel free to contact my office as I would welcome the opportunity to further discuss this bill with you.

Sincerely yours,

Theodosia A. Tamborlane

TAT:cr
cc: Pat Nagle, Committee Aid, Assembly Judiciary Committee
Encl.

Theodosia A. Tamborlane
COUNSELORS AT LAW

THEODOSIA A. TAMBORLANE, ESQ.

Ms. Tamborlane has broad-based expertise in the health law field, specializing in certificates of need, reimbursement, licensing, employment matters, joint ventures and corporate reorganization for health care providers and physician contracts and medical staff issues. She is the Principal in her firm which specializes in health law. Ms. Tamborlane was previously Of Counsel with Riker, Danzig, Scherer & Hyland. She also served as Deputy Attorney General, assigned to the New Jersey Department of Health.

Ms. Tamborlane is the First Chair of the Health and Hospital Law Section of the New Jersey State Bar Association, a member of the Board of Trustees of the New Jersey Bar Association, Legislative Chair of New Jersey Healthcare Financial Management Association, and a member of numerous health care organizations and associations, including The National Health Lawyers Association, the American Academy of Hospital Attorneys, and The American Society of Law and Medicine.

Ms. Tamborlane serves as an adjunct faculty member at UMDNJ-Robert Wood Johnson Medical School and at Seton Hall University Law School, where she teaches Legal Medicine. She is an editor for <u>RN Magazine</u> and the <u>New Jersey Lawyer Magazine</u>, as well as an Advisor to the Citizens' Committee on Biomedical Ethics and member of the National Legal Committee of the American Association of Homes for the Aging. In addition, she has authored many articles and is a frequent speaker at state and national health law conferences.

The clients Ms. Tamborlane serves include: hospitals, nursing homes, residential and ambulatory care facilities, home health care providers, doctors and other health care professionals, professional associations, and health care consultants. She also provides Special Counsel services to law firms in and outside of New Jersey.

Ms. Tamborlane graduated Summa Cum Laude from Drew University with a B.A. in Political Science. She was a Garden State Scholar and holds an M.P.A. degree in Human Resources Management, as well as a J.D. degree from Seton Hall University Law School.

"A PERSON'S RIGHT TO DIE — WHO DECIDES?"

By Theodosia Tamborlane, Esq.

Senate Bill No. 1211, entitled "New Jersey Advance Directive for Health Care Act" is currently pending before the New Jersey Legislature sponsored by Senator Gabriel Ambrosio. This proposed legislation would allow an individual to execute a "Living Will" through either a proxy directive, an instructive directive, or both. A proxy directive designates a health care representative who would then act when an individual is determined to lack decision-making capacity. An instructive directive would contain a person's wishes for the withdrawal, withholding or administration of health care when the individual would come to lack "decision-making capacity." No longer will a person have to be declared incompetent before a surrogate decision maker can act in his/her behalf.

A proxy directive and an instructive directive can be made in one document or can be in separate documents. Each must be signed by an individual and dated in the presence of two adult witnesses who attest that the person is of sound mind and free from duress or undue influence at the time of signing the document. The person to serve as a designated health care representative is prohibited by the act from being a witness.

If an individual wishes to instruct that artificially provided fluids and nutrition not be provided, he or she must specifically state this fact in the directive. If there is no mention that the withholding of withdrawal of artificially provided fluids and nutrition is the desire of the person completing the directive, this act would prohibit a health care representative from making the determination, even if the health care representative and the physician would determine that the withdrawal/withholding of fluids and nutrition would be in the patient's best interest.

The determination regarding a patient's lack of decision-making capacity is made by the patient's attending physician and the health care representative but such determination must be confirmed by one or more other physicians unless the attending physician and the health care representative agree that the patient's lack of decision-making capacity is "clearly apparent." If the attending physician calls in a confirming physician and a decision is that the patient lacks decision-making capacity because of a mental or psychological impairment or a developmental disability and the attending physician and confirming physician have not had specialized training or experience in diagnosing such conditions, there is an affirmative obligation under the act that they seek out one or more physicians who have had appropriate specialized training or experience to make the confirming diagnosis. The bill makes no reference as to how the cost of all the confirming specialists is to be paid.

WITHHOLDING TREATMENT OTHER THAN NUTRITIONAL

If the terms of an advance directive request the withholding or withdrawal of life-sustaining treatment, other than artificially provided fluids and nutrition, such treatments may be withdrawn or withheld *only* under the following circumstances:

- When the life-sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;
- When the patient is permanently unconscious as determined by the attending physician and confirmed by a second qualified physician;
- When the patient is in a terminal condition as determined by the attending physician and confirmed by a second qualified physician. (Terminal condition is defined as a prognosis of life expectancy of six (6) months or less, with or without the provision of life-sustaining treatment, or the terminal stage of a fatal illness, disease or condition regardless of life expectancy.)

If none of these three conditions is met, but the patient suffers from a serious irreversible illness, regardless of what instruction the patient has given, prior to withholding or withdrawing treatment, the attending physician must seek consultation of an institutional or regional review body. Life-sustaining treatment may be withheld or withdrawn for such patients only after there is a determination made by an institutional or regional committee.

EXTERNAL REVIEW REQUIREMENTS

The institutional or regional review committee is to advise the physician whether it believes:

- That the withholding or withdrawal of the medical intervention would be in conformity with the requirements of this law;
- Whether such withdrawal or withholding of treatment would be within the scope of the patient's advance directive;
- Whether is may be reasonably judged that the risks and burdens associated with the medical intervention to be withheld or withdrawn outweigh its likely benefits;
- Whether it may be reasonably judged that the imposition of the medical intervention would be inhumane.

The bill makes no reference as to

- who will be eligible to serve on the committee;
- how many regional committees are to be established;
- what is to be the geographical area served by the regional committee; or
- how the committees and/or committee members' expenses will be funded.

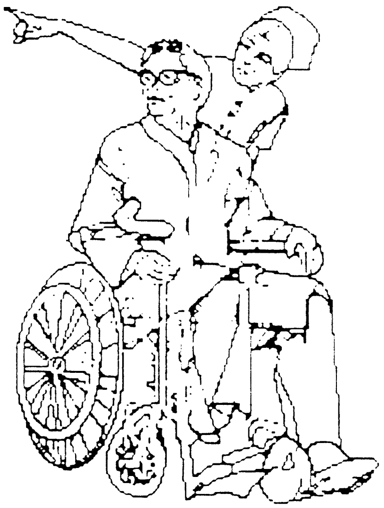
Upon the issuance of a determination by an institutional or regional review body, a health care representative, physician, nurse, or other health care professional who believes the review body's advice should not be followed may pursue an alternative course of treatment for the patient. However, if an alternative course is chosen that is not approved by the review body, the individual(s) who pursue such an alternative course will have no immunity conferred by this law and can be subject to both civil and criminal liability and discipline by state licensing boards. Review of the institutional or regional committee's decision is to be by a "public agency recognized by the law for this purpose" or by a court of competent jurisdiction. The institutional or regional reviewing bodies are to be subject to periodic accreditation and review. This bill does not define what public agencies to which appeals could be taken or what state agency would be responsible for accreditation of these committees. Further, it does not provide standards for accreditation, state who should sit on these institutional or regional review bodies, or what procedures such bodies should follow in their determinations or delineate why accreditation is necessary.

WITHHOLDING OF NUTRITION

If an advance directive states that artificially provided fluids and nutrition are to be withheld or withdrawn, such withdrawal or withholding may be undertaken ***only*** in the following circumstances:

- When the artificial provision of fluids and nutrition is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;
- When the patient is permanently unconscious as determined by the attending physician and confirmed by a second qualified physician;
- When the patient is in a terminal condition as determined by the attending physician and confirmed by a second qualified physician and the likely risks and burdens associated with the least burdensome treatment modality likely to be effective may be reasonably judged to outweigh the likely benefits to the patient from such intervention, and imposition of the intervention on an unwilling patient would be inhumane.

However, ***prior to*** implementing a decision to withdraw or withhold fluids and nutrition for as terminal patient, the attending physician ***must*** seek consultation with the institutional or regional review body or the public agency recognized by law. It is important to note that the terminal patient's directives which do not direct the withholding or withdrawal of fluids and nutrition will not be subject to mandatory review by an institutional committee. Thus, there is a double standard established by this legislation for terminal patients' medical decisions.



RIGHT TO CHOOSE

Health care institutions and health care professionals can decide whether they wish to participate in the beginning, continuing, withholding, or withdrawing of health care. The act allows institutions and professionals to transfer patients and the legislation mandates that if there is a disagreement among the patient, the health care representative, and the attending physician regarding the patient's decision-making capacity or the appropriate interpretation and application of an advance directive, the parties ***must*** seek to resolve the disagreement utilizing procedures established by the health care institution including, but not limited to, consultation with an institutional committee or a person designated by the institution to resolve such disputes. A health care professional or an administrator of a health care institution also independently may invoke dispute resolution processes themselves. If an agreement is not reached through the institutional dispute resolution process, resort to the courts can be instituted.

The health care institutions which will be governed by this legislation include all institutions, facilities and agencies licensed, certified, or otherwise authorized by State law to administer health care in the ordinary course of business, including hospitals, nursing homes, residential care facilities, home health care agencies, hospice programs, mental health institutions, or institutions, facilities and agencies for the developmentally disabled.

INQUIRIES MUST BE ROUTINIZED

This act imposes strict obligations on all health care institutions to adopt policies and practices whereby, at the time of admission, there will be a routine inquiry made as to whether a patient has an advance directive or has designated a health care representative. Institutions will also be obliged

- to provide appropriate informational materials to families regarding advance directives;
- to provide educational services to patients and families, including, but not limited to, family and social services, self-help and advocacy services, employment and community living, and the use of assistive devices;
- to consult with the attending physician to ensure that this information is discused with the patient and a patient's representative; and
- to adopt practices as necessary to inform all health care professionals of their rights and responsibilities under this act.

DOH RESPONSIBILITIES

The Department of Health has been given responsibilities under this Act to establish annual reporting and data gathering procedures to develop information from health care institutions regarding advance directives, with such information to be collected in a manner to assure confidentiality of patient records. The Department is also to evaluate the implementation of this legislation in concert with the State Commission on Legal and Ethical Problems in the delivery of health care within five (5) years. In addition, both the Office of the Ombudsman and the Office of the Public Guardian are to oversee the implementation of this Act.

While the Act does provide civil and criminal immunities for health care professionals, it also allows for discipline by professional licensing boards when a health care professional willfully fails to act in accordance with the requirements set forth in S.1211. A health care institution can be subjected to fines of not more than $1,000.00 for each offense if the institution is found to have willfully failed to comply with the act. There is no definition as to what would be deemed willful failure under the act.

The act contains two exemptions; the first is for private, religiously-affiliated health care institutions which may decline to participate in withholding or withdrawing of life-sustaining treatment. However, such institutions must communicate their policies to the patient and his family or health care representative prior to or upon the patient's admission to the facility or as soon as practicable thereafter. Second, there is an exemption for emergency personnel whereby they are not required to withhold or withdraw emergency care in circumstances which do not afford reasonable opportunity for review and evaluation of an advance directive without endangering the life of a patient.

COMPLEXITIES ABOUND

In summary, this proposed legislation establishes a complex scheme with varying standards for the withholding or withdrawal of treatment. This legislation sets forth multi-level procedures for directives with or without nutrition and fluids and requires health care representatives and health care providers to consult medical experts, institutional or regional review boards, or state agencies prior to carrying out a patient's wishes for withdrawal or withholding of treatment, depending on the patient's medical or psychological condition. No other state has enacted living will legislation which has the complexity and the potential to increase health care costs to the same degree as does S.1211. Many amendments are needed to streamline this bill so that patients, physicians, and health care institutions are not subject to excessive regulation and the intrusive presence of the state government at the bedsides of those who refuse medical treatment.

Theodosia Tamborlane, Statehouse Editor, is an attorney in private practice.

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OFFICE OF GOVERNMENT AFFAI
COMMISSION ON LEGISLATION AND CIVIC ACTIO

Agudath Israel of America
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December 3, 1990

MEMORANDUM

TO: Members of the New Jersey Assembly Judiciary, Law and Public Safety Committee

FROM: David Zwiebel, Esq., Director of Government Affairs and General Counsel, Agudath Israel of America

Rabbi Yakov Dombroff, Director, Agudath Israel of New Jersey

SUBJECT: A. 1413/S. 1208, the "New Jersey Declaration of Death Act"

Agudath Israel of America is the nation's largest grassroots Orthodox Jewish movement, with chapters in 30 states around the country. One of our most active state chapters is Agudath Israel of New Jersey, with constituents in more than half of New Jersey's counties.

A central function of Agudath Israel's national office and its various affiliated state chapters is to advocate the religious interests and rights of observant Jews throughout the United States. In that connection, we respectfully submit this memorandum to convey our strong support for A. 1413/S. 1208, the proposed "New Jersey Declaration of Death Act."

This bill, currently pending before the Assembly Judiciary, Law and Public Safety Committee, is designed to accomplish a dual purpose: to establish as a matter of statutory law the various clinical criteria upon which a determination of death is to be made; and to accommodate the sincerely held beliefs of those individuals who object on religious or moral grounds to a determination of death based upon irreversible cessation of entire brain function. It is this latter feature that makes the bill so attractive from Agudath Israel's perspective, since many Jewish religious authorities reject the concept of "brain death" and would counsel their followers that only the traditional cardio-respiratory criteria are an acceptable basis for determining death.

For those in our community who follow the view that cessation of brain function alone does not constitute death as a matter of religious law, imposition of a uniform state-mandated "brain death" standard would infringe upon fundamental religious liberties. Hence the critical need for a "religious exemption" from uniform brain death criteria.

Such an exemption exists in New York, by virtue of a New York State Department

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of Health regulation adopted in 1987, which requires health care facilities to develop policies for the "reasonable accommodation" of a patient's religious or moral objection to any determination of death based on neurological criteria. Indeed, New Jersey itself is no stranger to this issue; in 1984, in order to protect the religious and civil rights of persons who do not accept brain death criteria, Governor Kean vetoed a uniform determination of death bill that would have established cessation of brain function as a basis for determining death but contained no religious exemption. (I take the liberty of enclosing a copy of a January 1984 letter from W. Cary Edwards, then Governor Kean's chief counsel, to Agudath Israel of New Jersey, expressing the basis of the Governor's veto.)

The general public policy of accommodating minority religious viewpoints is certainly unobjectionable in American tradition and law. If anything, it is a constitutional mandate. Nonetheless, some claim, the costs of accommodation in this particular instance -- in terms of its impact upon the availability of organs for transplantation and upon the need for medical uniformity — are too high. Upon consideration, however, we think it should be obvious that these perceived costs are largely illusory.

The transplant issue is entirely a red herring. As a matter of law, no transplant may be performed without the consent of the organ donor or his representative. Surely those who have religious or moral objections to brain death would volunteer no such consent. Stated otherwise, the bill's accommodation provisions would affect only those individuals who in any event would not donate their organs. Hence the bill's impact upon transplants would be absolutely nil.

The issue of medical uniformity is likewise non-substantial. This becomes obvious when one considers the alternative to this bill -- a "one size fits all" approach to death determination that leaves no room for accom-modating religious or moral objections to brain death. That alternative would almost certainly lead to controversy, litigation -- and ultimately the very antithesis of uniformity, as some doctors and hospitals will respect individual beliefs while others will not.

What the proposed legislation provides in the place of chimerical uniformity is reliable clarity. So long as the bill's procedures are followed, health care providers are on safe ground, insulated against potential legal claims and community disapprobation. Ultimately, we believe, the approach adopted in this bill will prove highly popular in the medical community.

The New Jersey Bioethics Commission, comprised of a broad spectrum of moral and medical viewpoints from all across the state, conducted several hearings on this proposed bill and recommended its adoption unanimously. Its passage would mean a great deal to the growing Orthodox Jewish community in New Jersey. We believe it should also mean a great deal to anyone concerned with the fundamental principle of religious freedom. Respectfully, we urge the Committee to support the bill in its entirety.

Many thanks for taking the time to consider our views.

D. Z.
Y. D.

STATE OF NEW JERSEY
OFFICE OF THE GOVERNOR
TRENTON
08625

THOMAS H. KEAN
GOVERNOR

W. CARY EDWARDS
CHIEF COUNSEL

January 19, 1984

Rabbi Yakov Y. Dombroff
Agudath Israel of America
1169 Elizabeth Avenue
Elizabeth, New Jersey 07201

Re: "Uniform Determination of Death Act" S-140

Dear Rabbi Dombroff:

Thank you for your recent correspondence, in which you expressed your strong opposition to Senate Bill No. 140, which would have authorized determinations of death based upon the cessation of brain activity.

As I understand your letter, your opposition to this legislation stems from a belief that the definition of death involves serious ethical, moral, legal and religious issues which should not be legislated. You also stated that "according to both Jewish law and the common law, death occurs only upon the cessation of cardiac respiratory activity and that therefore a statute such as S-140 would violate the First Amendment rights of Orthodox Jewish citizens of the State of New Jersey." Finally, you suggested the adoption of an amendment which would incorporate an "exemption clause" for those who do not accept a legislative definition of death.

I am very pleased to inform you that Governor Kean has recognized the objections put forth by you as well as other religious organizations, and accordingly he conditionally vetoed this bill to reflect those concerns. Although he agrees with the intent and purpose of this bill, he also believes that it may violate the First Amendment "freedom of religion" rights of certain citizens of New Jersey. In order to protect the religious rights of all New Jersey citizens, the Governor recommended that this bill should be amended to include an exemption clause for those who do not accept a legislative definition of death which contravenes the basic tenets of their religious beliefs.

However, because the Legislature has chosen not to respond to this bill as per the Governor's recommended amendments, it did not become law.

Once again, thank you for your serious consideration and cooperation with respect to this proposed legislation. Your input is always welcome.

Sincerely,

W. CARY EDWARDS
Chief Counsel

cb/jj