# P U B L I C  H E A R I N G

before

## ASSEMBLY HEALTH AND HUMAN RESOURCES COMMITTEE

To examine policy issues relating to
Acquired Immune Deficiency Syndrome (AIDS)

February 9, 1989
Room 341
State House Annex
Trenton, New Jersey

**MEMBERS OF COMMITTEE PRESENT:**

Assemblyman Harold L. Colburn, Jr., Chairman
Assemblywoman Maureen B. Ogden
Assemblyman Thomas J. Deverin
Assemblyman George J. Otlowski

**ALSO PRESENT:**

David Price
Office of Legislative Services
Aide, Assembly Health and Human
Resources Committee



* * * * * * * * * * *



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

New Jersey State Legislature
ASSEMBLY HEALTH AND HUMAN
RESOURCES COMMITTEE
STATE HOUSE ANNEX, CN-068
TRENTON, NEW JERSEY 08625
TELEPHONE: (609) 292-1646

January 13, 1989

NOTICE OF A PUBLIC HEARING

THE ASSEMBLY HEALTH AND HUMAN RESOURCES COMMITTEE
ANNOUNCES A PUBLIC HEARING
TO EXAMINE POLICY ISSUES RELATING TO
ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

Thursday, February 9, 1989
Beginning at 1:00 P.M.
Room 368 of the State House Annex
Trenton, New Jersey

The Assembly Health and Human Resources Committee will hold a public hearing on Thursday, February 9, 1989, from 1:00 P.M. to 4:00 P.M., in Room 368 of the State House Annex, Trenton, New Jersey, to examine a number of public policy issues relating to acquired immune deficiency syndrome (AIDS). These will include: the effectiveness and cost of testing for the human immunodeficiency virus (HIV), current State policy on reporting cases of AIDS and AIDS related complex, existing and projected treatment and prevention programs, and selected related issues of concern to the chairman and committee members. The committee intends to hear testimony from individuals, agencies and organizations for the purpose of obtaining information and assessing the need for administrative and legislative initiatives.

Address any questions or requests to testify to David Price, Committee Aide (609-292-1646), State House Annex, Trenton, New Jersey 08625. Those wishing to testify are asked to submit nine typed copies of their testimony on the day of the hearing. The chairman may find it necessary to limit the number of witnesses and the time available to each witness at the hearing.

TABLE OF CONTENTS

TABLE OF CONTENTS (continued)

TABLE OF CONTENTS (continued)



* * * * * * * * * * *

mjz: 1-179

**ASSEMBLYMAN HAROLD L. COLBURN, JR. (Chairman):** I would like to start the public hearing, if I may. I apologize for the restricted accommodations in the State House. We have had to delay for a few minutes. I'm hoping that if the Chairman can hold out for the afternoon and part of the evening, we can give everyone a chance to speak who has asked to speak. Right now, the number is well over 40.

As you probably know, the purpose of this public hearing by our Assembly Health and Human Resources Committee, is to inform the members and the staff as to the many aspects of infection with the human immuno deficiency virus. The Committee members and the remaining members of the General Assembly, from time to time, must consider legislation having to do with the management of this widespread disorder and its difficult problems, as well as appropriations for the management of it.

Human beings have been subjected to plagues throughout history. I brought my copy of Sir William Osler's textbook, the edition of 1922, with me. It speaks a little bit of bubonic plague. I thought I would read you just a few sentences having to do with a portion of India:

"The distribution in India of the bubonic plague is remarkable chiefly in the Punjab, Bombay, and the United Provinces, which have a combined population of about 100 million. In these three provinces, between 1896 and the middle of 1911, about five-and-a-half million deaths from plague have occurred. In the remaining provinces of India, with a population of some 200 million, only about two million plague deaths have occurred." Then it goes on to describe other parts of India and other parts of the world where the plague took varying tolls, I suspect depending upon the populations and the habits of the people.

Now, in this particular situation, knowledge about this disease has evolved very rapidly. The cause has been

discovered; tests have been discovered. Of course, we are lacking effective treatments, but the progress in learning about this disease has been truly remarkable. As difficult as it is, and as impatient as we all are to do even better, it is amazing what has happened so far.

At this point, I would like to introduce the members of our Committee: Assemblywoman Ogden is sitting right over here; Assemblyman Tom Deverin is right over there. We are missing a couple of members who either can't make it, or who will come later. I am Harold Colburn. I am the Chairman of this Committee. David Price is our nonpartisan staff member -- right here. Mary Messenger is the Democrat staff member, and John Kohler is one of our Republican staff members. Suzanne Ulivi, over here, is another; Mike Torpey is over here. Ray Cox, who will speak later, is Assemblyman Kline's number one staff man, and Bill Naulty should be around here. He is my number one man. He must have gone over to help Senator Haines in the Senate, because he is not back there, and I might need his help.

I may have said earlier that over 40 people are supposed to testify today. I hate like the dickens to bring a bunch of people up here and not let them speak. So, if I can hold out, I think I am just going to stick around, even though other people may have to leave, and try to listen to everything. For those of you who are going to testify, or who would like to testify but can't stay -- who just absolutely run out of time -- we will accept any written testimony that you want to give us, and we will hold the record open for about 30 days, so if you want to send any, we will receive it.

I am going to ask you to try to be brief. I see charts and things, which always scare me a little bit. If we get too lengthy in any one area, we may have to meet with those people on a separate occasion, because there is just too much to go over.

I consider these hearings to be a learning experience for the Committee, and maybe for some of you. I have always asked that people respect each other's opinions, even though they may be very divergent. Believe me, I certainly don't expect to agree with all of you, but I do respect you, and I would expect that everyone would accord everyone else due respect and courtesy.

About three o'clock, we will temporarily adjourn the hearing. We have a Committee substitute bill to act upon. We will act on that, and then we will reconvene the hearing. For those of us who have been able to survive, and for those of you who have survived that long, we will go on and try to hear everyone. I appreciate your participation in this, and welcome your ideas.

I am going to call Dr. Coye first, and she can bring her retinue up with her. Good afternoon, Commissioner.

**COMMISSIONER MOLLY JOEL COYE:** Good afternoon. I just have to make sure that I am speaking into the right one of all of these contraptions here. (referring to numerous microphones)

ASSEMBLYMAN COLBURN: I know, it's hard to tell.

COMMISSIONER COYE: Thank you very much for convening this hearing, and good afternoon to all of the Committee members. I am glad to have the opportunity to appear before you. Let me start by thanking, very genuinely, you, as representative, Chairman Colburn, of the Legislature -- to thank the Legislature for their support. Because of it, we have the most comprehensive AIDS program in the United States. I think this has required a great deal of courage and understanding and time on the part of the Legislature, to make it possible for us to put together a program of this nature.

AIDS now is a part of the world fabric. It is the disease that is present in almost every country in the world. Those who are battling it, those who are involved in it, have

witnessed the full spectrum of human responses, from the most base to the most noble. There have been moments of great tragedy, and moments of tremendous triumph as well. Our responsibility in the face of this epidemic as public health officials, is to ensure complete information to everyone, for prevention, to provide full access to care, and for those individuals who actually die, to make sure that they are provided death with dignity.

That is the responsibility of our Department. In organizing those efforts, I have the assistance of our Deputy Commissioner, Christine Grant, and our still relatively new Assistant Commissioner, Bob Hummel. I have asked them to join with me today in presenting to you the information on the situation in New Jersey, the accomplishments of the Department, and the challenges that we still face. I will be following the order of the written testimony you have before you, but don't plan to read it because I am aware of the time limitations we face, and there is a tremendous amount of material that I need to cover.

Let me begin by discussing the scope of the epidemic in New Jersey. As you can see from the first chart -- and I believe you have this information in handouts, too -- by the end of January, we had almost 6000 cases of AIDS in New Jersey. In the last year, for which reporting is not even complete yet, we have diagnosed more than 1500 cases of AIDS. We project by 1990 -- not very far away -- that there will be 4000 new cases of AIDS diagnosed in that one year alone.

The rate of increase has slowed somewhat, but the absolute numbers -- the numbers of cases each year -- are continuing to increase. If you look at the next chart, this shows you our projections and estimations. We currently have slightly under 6000 AIDS cases, and we estimate that there are 87,000 people infected with the AIDS virus -- HIV -- in the State of New Jersey right now.

Our epidemic -- turning to the next chart, please -- is an epidemic that is very different from that in the U.S. as a whole. The chart up here shows you a comparison of what you may have separately in your handout, of cases in the United States and cases in New Jersey in comparison. What this shows us is that the epidemic in New Jersey continues to be unique. It is not like the epidemic throughout the country as a whole. In the nation as a whole, as we know, the gay population is over-represented. In New Jersey, it is IV drug use -- intravenous drug use -- that is the primary risk factor of concern. As a matter of fact, 57% of our cases are intravenous drug users. This leads to a particular problem in New Jersey -- and for this I would like to turn to the chart on pediatric cases -- which is that we have a large number of pediatric cases, and almost all of these -- 91% -- are born to parents who are at risk for AIDS, usually because either they are a drug user themselves, or because their partner, their spouse, is a drug user. Not surprisingly, what that shows us, what we would expect to find, is that we have a very high proportion of women with AIDS in New Jersey.

The next chart shows that only Connecticut matches us in the percentage of cases which are found among women. As a matter of fact, this data is for 1986 and, unfortunately, in 1987, the proportion due to women climbed to 20% -- so, one out of five cases. That suggests to us that we will continue to have with us an epidemic not only that contains the heterosexual spread from those who are drug users to their sexual partners, but a growing number of children as well, as a result of this pattern.

I would like now to turn to some unfortunate news that I need to share with you today. With the help of a Family of Surveys Grant from the Federal Centers for Disease Control, our Department has just concluded a statewide newborn survey for infection among newborns with the AIDS virus -- HIV. This is

the first time in the nation that a true statewide, population-based seroprevalent survey for HIV has been conducted. It represents the testing of nearly 100% of New Jersey newborns -- of babies born in New Jersey -- over a three-month period in 1988. Of 29,309 babies born during the survey period, 144, or about one-half of 1%, had antibodies to HIV. It is accurate to say that of these infants, one-third to one-half will actually, themselves, turn out to be infected. What we are detecting when we do this blood test, is the presence of antibodies that come from the mother. It means that the mother is infected with the virus, and somewhere less than half of their children actually will turn out to be infected themselves. The remainder of the babies are only carrying the antibody from the mother, but will, themselves, not turn out to be infected. So, what this data really tells us, is the number of women giving birth who are infected with the virus, and the number of babies who are exposed and possibly infected.

New Jersey now ranks second to New York in the number of reported pediatric cases, even though we are fourth in the country -- after New York, California, and Florida -- in the total number, when you count in the adults. So we have a particular problem in both women and children.

As the chart shows you for the results of our survey, we, in fact, find that almost every county in the State has children born who have been exposed to the HIV virus. You can see that a few counties have very high levels, well above the statewide average. These are very disturbing figures, but they are going to be very, very important in assessing our present efforts in this area.

We have a lot of existing programs to help babies who are born who are infected with the AIDS virus. We have nationally recognized case management programs. We have demonstration projects with grants that have established

regional treatment centers. We have established care standards for many disciplines, including medical attendants. We published a great deal in terms of education and risk prevention information. We will be expanding the development of care, counseling, and support centers with another grant that we have received from the Centers for Disease Control.

In response to this news, which is of great concern to us, we will be assembling a panel of clinical experts to advise us on how we should further develop our programs for the comprehensive care of the children who are born with this condition of exposure, or those who turn out eventually to be infected.

Let me turn -- given that grim news -- to the programmatic work in the Department in response to this. Again, I would like to point out that our ability to respond to this is often, and largely conditioned by the support provided by the Legislature, and I would like to recognize the really outstanding support that the Department has received in the past. There are a lot of people you are going to hear from this afternoon, people who are even more on the front line than we are; people who are dealing day to day with taking care of people who are infected with HIV, or going out working with the community groups to do the education. So, you will hear from people who are even more day to day involved than I am. We see the Department, really, as the hub of all of these activities, relying on private health professionals, on communities, on hospitals, on drug centers, on local health officers, and trying to provide technical assistance, support, grant moneys, and other forms of assistance to them.

Our response is tailored to the shape of the epidemic. As you can see on this list of our programmatic work, our first task was to define the risk factors, and I showed you an outline of what we did determine through our research to find the major risk factors; mainly IV drug use

ahead of any other. We also have targeted high risk groups, and we have been the first state in the nation to do some very innovative programs with outreach into the drug addict community, where we get people who used to be drug addicted, who are now drug-free, to help us go out on the street to talk with the people who are currently using drugs, and get them into treatment.

We established a hotline for AIDS which had 14,000 calls last year. In 1987, we developed curriculum guidelines for students throughout the State, and many schools in the State have adopted that curriculum. In 1986, we developed the first managed care network with a grant originally from the Robert Wood Johnson Foundation, and eventually from the Department of Human Services. We got a waiver from Medicaid so that we could reimburse properly for that kind of care.

I would like to turn to some of our future plans, which depend on the last item down there, which is the creation of our Division of AIDS Prevention and Control. If we may have the next chart, please. (speaking to assistant who is working with charts) In planning for the future, we have identified specific goals that will guide our efforts. First of all, all citizens of this State will be provided with basic, accurate, and clear information as to how the HIV virus is spread, as well as frank and forthright information on the necessary precautions in order to avoid exposure. Counseling and testing will be universally available to any individual who is concerned that he or she may have been exposed to the virus.

The Department is developing, in partnership with health care providers, a statewide system of managed care accessible to all individuals struck by the epidemic, so that there is no point in the health care system where a person would enter and not receive appropriate care or referral.

Housing and other support systems will need to be developed, especially for those who lack the resources to

maintain their family structure and, unfortunately, you will hear from many people this afternoon who have witnessed the deterioration or decomposition of families, as first the father dies, the mother dies, and then the children die.

Finally, research will continue, especially the research that makes it possible for us to do important planning. The organization of the Division in order to achieve these goals will be based on prevention, counseling and testing and contact notification, community support, health care services, and research services.

Let me turn now to what we are doing in prevention, education, and training. You have in your handouts a piece of paper that looks like this, which lists, by category, some of the groups we have provided training and prevention activities for. We have trained a total of 34,000 individuals in Department programs in the last year. This included: students and faculty in the public schools; many different task forces at the county and city level; work with the correctional facilities, with colleges and universities to train both faculty and students there, with emergency medical service personnel. We have trained more than 6000 EMP and first aid squads and other emergency service personnel. We have trained health care professionals, mental health clinics. We have had an especially intensive effort to train many members of the churches in the State, because the churches, in turn, have been wonderful sources of support for us, and have really been leaders in helping to develop the community support that is critical to our work.

We have training programs for minority associations. We have important responsibilities now for training government workers under the new executive order in that regard. And of course, we train physicians and dentists. So, we have put a lot of effort into this area. We have also worked with 27 community-based organizations to develop plans of action. I

mentioned the hotline. We also have educational materials and PSAs for the media. We developed this year, for the first time, with the Medical Society, clinical guidelines, so that physicians have something to refer to and depend upon. We have special outreach for teen-agers, with PSAs in our program called, "Bands to Beat AIDS," where we get rock band stars to work with us doing PSAs and posters. I think we might have a copy of one of those posters here to show you. We have had Kool and the Gang, and a number of other rock bands that have worked with us on this.

I mentioned the work we are doing with government employees. We are also working with the local health officers. We have offered training to 180 local health officers, and are developing a manual for them to use in their programs.

That gives you a quick overview of our work in prevention and education. Let me turn now to counseling and testing. This chart shows you the tremendous increase in the number of people who are receiving counseling and testing through our efforts. In 1988, 12,000 people received counseling and testing. Of those, 14%, or about 1700, were positive for HIV antibodies -- were infected with the HIV virus. Right now, we have 12 sites around the State for counseling and testing. By the end of this year, we will have four more.

Importantly, we are also offering counseling and testing at drug treatment centers, sexually transmitted disease clinics, family planning clinics, and in prenatal programs, so that we don't have to always just set up special sites for this counseling and testing, and so that it can be a routine part of care for many people when they have contact with the health care system.

In 1989, we estimate that 75,000 to 100,000 people will receive counseling and testing. This is a massive effort,

and is absolutely important. It is a front line effort to make sure that we identify individuals, and I am sure, Dr. Colburn, that you know clinically that it is becoming more and more important because we now have something we can do clinically for people when they come in. Often, it is very important to provide prophylactic treatment to try to prevent the onset of pneumonia and other conditions. So, it is very important that we diagnose people early in the course of their infection, and not wait for them to come to a physician.

We also, in the last year, have developed a very important program, which is to notify the partners of people who are identified as positive. This is the Notification Assistance Program. We estimate this year that between 2000 and 4000 people will be notified as a result of this program. Let me tell you, it is one of the most difficult programs you could possibly mount. I am sure Mr. Hummel could give you lots of details of the problems entailed, but it is not an easy job to go out and track people down and confront them with this information. It is a wearying, really high stress occupation. I can't think of anything I would less rather do, than have to break this news to people. We are very glad that we have been able to mount an effort in this regard.

The next area for us is surveillance, and let me define "medical surveillance," because sometimes this word is overused. Surveillance means very simply, monitoring the epidemic -- collecting the data through reporting usually, or research on all aspects of the occurrence and spread of AIDS. As you know, AIDS has been reportable in New Jersey since 1986. Our Surveillance Unit contacts all of the hospitals and other health care facilities on a weekly basis, tracks the course of the epidemic, and conducts a three-month status follow-up. For each case that is reported, they go back to find out what is happening three months later. We do this with the cooperation of the University of Medicine and Dentistry of

New Jersey, which has a grant for operating this system for their hospitals. This is one of our most important ongoing efforts.

That information, together with other information, goes, in turn, to our Data Analysis Unit, which analyzes the data and prepares a monthly statistical report. I believe you receive copies of that from us on a periodic basis, giving you some idea of the increases each month. That Data Analysis Unit also designs special studies, and we would not have been able to conduct studies such as the newborn study that I just reported without the help of this Data Analysis Unit.

I would like to mention here -- even though this is not a part of the AIDS Division -- the very important work done by our laboratory, in the work we do to characterize the nature of the AIDS epidemic. If we had not had a laboratory that was in the forefront of diagnostic techniques and building capacity for diagnosis of HIV infection, we never could have been the first State to do a statewide newborn survey. So, it really is important to have that ongoing capacity in our laboratory.

You also have in your handout two pages describing the organization of health care for people who are HIV infected. This is important, because it gives you some idea of the complexity in the range of services we are trying to mount for people who are HIV infected. We begin with the acute care hospitals, and you have probably heard a lot about the problems the hospitals have. But the nature of those problems have changed in the last year. A year ago when I talked to you, we were talking primarily about backup on the inpatient side in the hospital -- on the wards. Today, because so much of the treatment of the people who have AIDS is becoming outpatient treatment, where people can come in to see the doctor but live at home, it is the outpatient clinics that are jammed in the hospitals. Even though there are still some problems on the inpatient side in some of our hospitals, we are seeing a growing problem on the outpatient side:

Skilled nursing facilities, where one is already operating and a second one has received a Certificate of Need-- We hope that more of those may be established in the future; residential care for adults in our Drug Treatment Centers and the first Medical Day-Care Program in the country -- New York followed us shortly afterwards in developing a program; pediatric care -- residential facilities such as St. Clare's, which you probably know of in Elizabeth, but also now in Jersey City and Monmouth, others are opening.

On the second page of that listing, you will see a very important point, which is assuring a continuum of care; that people do not get bounced around or lost to the system. This takes case management, which has really been pioneered in New Jersey, and is possible financially, in part, because of the Medicaid waiver.

We have also given a Certificate of Need for the development of home health care, and many existing home health care agencies are offering care to AIDS patients. We are very glad to see that mainstreaming effect in those home health care agencies. Hospice care is offered. There is one dental clinic already established for HIV infected patients, with a second, we hope, soon to be under way. We have a grant program, which was announced yesterday, which will provide additional money for residential care and housing for adolescents, for mothers and babies, and for adults, who are HIV infected. Finally, we provide support groups and counseling for people who are infected with HIV.

I think you can see from the length of that list and the complexity of the kinds of services, how difficult the effort we are mounting is.

Let me turn to the Medical Research Unit.

ASSEMBLYMAN COLBURN: Okay.

COMMISSIONER COYE: The Medical Research Unit is the heart -- as you see in our newborn survey -- of finding out

what the scope of the problems are today and what we are likely to face in the future. Currently, our Medical Research Unit is involved in the Family of Surveys, which does large population testing such as the newborn study I just described to you. The Newark area is one of 30 that is nationally included in this five-year project. When I say, "the Newark area," it is the Newark SMSA, so it is much larger than just the City of Newark. These blinded serosurveys help to determine the extent of the disease and its geographic and demographic profile. In other words, basically what we are doing is testing blood samples from a very wide range of situations, in order to get some idea of how many people are infected, and what their characteristics are in terms of their health status, their age, their sex, their race, and the kinds of health care institutions they are going to. These are long-accepted processes and procedures that help public health to focus our preventive efforts where they will be most effective.

Last year, we also conducted a survey of this type in our Sexually Transmitted Disease Clinics throughout the State. This showed a statewide infection rate in STD clinics of 8.5%. That means that 8.5% of all the people who are coming to our Sexually Transmitted Disease Clinics are infected with HIV. It was as high as 13% in Essex County. We are currently repeating that in various parts of the State in STD clinics; we are also looking at, in our laboratory, premarital blood specimens; and we are working with the State Medical Examiner to develop a survey of medical examiner cases. This gives you an idea again of what you can do if you have a laboratory on a large scale that is able to gear up for this.

We are also working on a very important invention here in New Jersey, which is developing a finger-stick method to do the blood tests, rather than having to draw a full blood sample, which we think would make it not only faster and cheaper, but would also make people who cannot stand to have

their blood drawn more likely to be willing to be tested. So we are very hopeful, and I have to give credit to our own AIDS Division staff for coming up with this idea. We and the Centers for Disease Control are very excited about this. We think there are some real possibilities.

We are also doing a questionnaire survey of health and social needs of a random sample of AIDS patients. This is very important, to find out where they are, how they are living, and what they need.

We are studying follow-up on blood transfusions, and we are also following a group of drug users who had HIV tests in '84 and '85, to see how many more people are becoming positive. We are studying -- and this is a question that is very puzzling -- what the rate of death may be for people who are infected with HIV, but who do not die of a disease that fits the AIDS diagnosis -- the case definition that CDC has issued. New York has already done a study like that, and we are doing a study. We suspect it will show us that there are far more deaths related to HIV infection than we are currently reporting in our current methods for counting.

Finally, we are particularly looking at the relative risk in minority populations, and will be continuing to follow that in this State.

Our last unit is the Community Support Unit. There is not a handout with this one. The Community Support Unit is the unit that organizes care; for example, the development of homes for children with AIDS and some of the residential facilities that I discussed with you previously. Obviously, the work they do faces the difficulty of the "NIMBY" -- the not in my back yard syndrome -- just the way some of our environmental health efforts do. They have done wonderful work in trying to overcome that and helping us to place facilities where we need them.

This is a long, but only partial list of what we are currently doing and what we plan to do. There are many other challenges and initiatives that I could present to you if we were not limited by time. But what is clear is, New Jersey, perhaps more than any other state in the country, has answered the challenge of this epidemic with a comprehensive set of programs. We have developed these with your cooperation and assistance, and we are proud of the high quality continuum of services that we are providing for all citizens of the State.

I thank you for your cooperation, but remind you that we are going to have to continue to be vigilant and aggressive in this struggle. We are going to have to continue to involve all of the people of New Jersey -- all of the community groups, the church groups, the emergency medical service personnel, the physicians, the dentists -- everyone in the State, in understanding the hazards of this epidemic and doing battle with it.

Thank you very much.

ASSEMBLYMAN COLBURN: Thank you. I am going to suggest that the Committee members write down their questions on this very complicated subject, and not necessarily pose them at this time. I think there are questions that we will have to have answered on a continuing basis. Unless there is something that was not clear in the Commissioner's presentation, I would appreciate us going into those at another time.

Mrs. Ogden, do you have anything to clarify the presentation?

ASSEMBLYWOMAN OGDEN: No.

ASSEMBLYMAN COLBURN: Mr. Deverin?

ASSEMBLYMAN DEVERIN: Just that it was a very good presentation.

COMMISSIONER COYE: Thank you very much. I will be in and out a little bit, but will probably have to leave. However, Ms. Grant and Mr. Hummel will be here to answer your questions later on. Okay?

ASSEMBLYMAN COLBURN: Fine. Thank you. Mr. Otlowski?

ASSEMBLYMAN OTLOWSKI: No, thank you.

ASSEMBLYMAN COLBURN: Okay.

COMMISSIONER COYE: Thank you very much.

ASSEMBLYMAN COLBURN: Thank you. Doctor-- I'm sorry, I am going to have trouble with your name.

**J O H N S E N S A K O V I C, M.D.:** (speaking from audience) John Sensakovic. (witness pronounces his name for the Committee)

ASSEMBLYMAN COLBURN: Wow! Sensakovic, right? Please come up and have a seat.

ASSEMBLYMAN DEVERIN: That's an old Slavic name.

ASSEMBLYMAN COLBURN: Dr. Sensakovic is Director of Medical Education, St. Michael's Medical Center, Newark, and a member of the New Jersey Task Force on AIDS of the Medical Society of New Jersey.

DR. SENSAKOVIC: Correct.

ASSEMBLYMAN COLBURN: Thank you for coming.

DR. SENSAKOVIC: Thank you for having me.

I think all of you should have a copy of the--

ASSEMBLYMAN COLBURN: It is coming right along.

DR. SENSAKOVIC: --brief report we have prepared. I am John Sensakovic. I am an infectious disease specialist. I am the Director of Medical Education at St. Michael's Medical Center, and I am one of the physicians who served on the Task Force of the Medical Society of New Jersey. I am here to testify on behalf of the Medical Society of New Jersey.

The Medical Society of New Jersey's Task Force on AIDS was organized to develop a consensus viewpoint on the important medical issues regarding AIDS. The Task Force, under the Chairmanship of Dr. Leon G. Smith, was comprised of physicians, researchers, and representatives of nursing, education, hospital administration, law, and the insurance industry. The Task Force has spent long hours considering a large variety of

AIDS issues, many of which are listed in the booklet entitled, "AIDS - Information for Physicians," which you should all have a copy of.

ASSEMBLYMAN COLBURN: We have received that.

DR. SENSAKOVIC: What I would like to do is briefly outline some of the important issues that are contained in outline form in that booklet.

As regards education, in the absence of a cure, education is, indeed, a principal means in dealing with the disease. Cooperative efforts between the Medical Society of New Jersey, the Academy of Medicine of New Jersey, and the New Jersey State Department of Health have been extremely successful in this area to date. A recent survey has shown that physicians' attitudes towards AIDS are not significantly changed by legislative mandate. On the other hand, a more recent survey has shown that education does change physicians' attitudes and involvement with AIDS patients. The educational efforts regarding AIDS must be continued and expanded.

They must include physicians, dentists, health care workers, individuals engaging in "risk behaviors," the general public, and schoolchildren before they have the opportunity to engage in these risk behaviors.

As regards HIV testing, HIV testing should be performed whenever clinically indicated. Confidentiality of such test results must be a principal concern. Informed consent should be obtained, and appropriate pre and post-test counseling are essential. However, a need to obtain an informed written consent should never be an obstacle to testing whenever it is clinically indicated.

Reporting of HIV positive patients: Provisions for reporting all HIV positive individuals to the New Jersey State Department of Health should be developed. Such reporting would allow more complete prevalence analysis of infection with the virus. Additionally, such reporting would allow tracking and

counseling by the New Jersey State Department of Health of "needle-sharing" partners of the positive individuals or other contacts of the individuals who would be at risk of infection.

Physician immunity in reporting: AIDS is a public health problem, and although confidentiality is a primary concern, reporting of HIV positive individuals and tracking and counseling significant contacts is essential to control this epidemic. To encourage such reporting, tracking, and contact counseling, physicians must be assured of immunity from any liability associated with such reporting and tracking.

Distribution of free needles to addicts: Although limited success has been reported by some "free needle" and "needle cleaning" programs, the Medical Society does not recommend this approach. Such funds could better be used for increasing and expanding drug treatment centers, especially the drug-free programs, to increase their availability and decrease the waiting times.

Intermediate care facilities: Long-term care facilities, both nursing home and minimum care facilities, are urgently needed for AIDS patients. Hospitals are being overwhelmed, not only with AIDS patients who are acutely ill, but also with patients no longer acutely ill but in need of placement because of lack of a home to go to or refusal of a relative or a friend to accept the patient. These placement problems overburden the system, are costly, and utilize hospital beds that can be better utilized for acutely ill patients. Adequate intermediate care facilities are urgently needed, both for nursing home care and for minimum care residences for AIDS patients.

And finally, on the concern of refusal to treat by physicians: The Medical Society recognizes the right of physicians to determine which patients they will serve within the scope of their practice. However, categorical refusal to treat patients with AIDS is morally and ethically unacceptable.

Education can increase the involvement and ability of physicians to care for AIDS patients. We are currently not aware of any documented cases of categorical refusal by a physician to treat AIDS patients in New Jersey. From the earliest cases, when little was known and fears were the greatest, medical professionals have responded with the care and compassion we have come to expect. We need your help to continue these efforts in the battle against this terrible disease, in all of the issues that have been outlined.

I thank you very much.

ASSEMBLYMAN COLBURN: Thank you. Any brief questions? (no response) I want to say that I think in the area of who should be tested and how you protect, or take care of the health care professionals who treat the patients-- I certainly think that is a difficult area. You know, I realize that this has been addressed, but I think that as time goes on, we have to keep rethinking our attitudes toward all of these things, because new information does come about.

One other thing I just wanted to mention: I feel that the Medical Society would be able, and willing, to cooperate with any recognized group that is trying to deal with this problem, and would urge that they do cooperate with anyone who is a recognized -- or who has a recognized group that is dealing with the problem. Those groups will emerge as time goes on. They may be people who have AIDS, or they may be people dealing with drug abusers, and so on and so forth. But I think the Medical Society can be a great resource to those groups, and I think maybe the educators, that is in public education, and even in parochial education, could make use of the Medical Society's and the Academy of Medicine's resources.

This is a big effort that requires a lot of cooperation and a lot of understanding among all of us. We could devote just about all of our time to this, it is such a big thing. I think the Medical Society has taken some big steps forward.

I read this whole pamphlet. Has it been sent out to all of the members yet? It is dated January. Have we all received it? I don't remember getting it in my office.

DR. SENSAKOVIC: It is in the process of being mailed now.

ASSEMBLYMAN COLBURN: But it has not been fully mailed?

DR. SENSAKOVIC: Right.

ASSEMBLYMAN COLBURN: Okay. All of our Committee members got this; our staff people have it. It's pretty informative.

Do the labs that do the tests and are accredited in New Jersey report positives to the State Health Department?

DR. SENSAKOVIC: It is my understanding now that positive tests alone are not reported. This is one of the issues we feel must be addressed.

ASSEMBLYMAN COLBURN: Just maybe in numbers, if nothing else. Okay. Well, we have another person I can ask that of. I just wondered.

ASSEMBLYMAN OTLOWSKI: Doctor, excuse me--

ASSEMBLYMAN COLBURN: Yes?

ASSEMBLYMAN OTLOWSKI: In the event of blood testing by laboratories of syphilis and other kindred diseases, they are immediately reported to the State Health Department. Isn't that a fact?

DR. SENSAKOVIC: Certain diseases, such as a positive syphilis test, are indeed reported to the State Health Department.

ASSEMBLYMAN OTLOWSKI: Dr. Sensakovic, in your opinion, why isn't there a law compelling the reporting of this to the State Health Department, to help with the tracking system you are talking about?

DR. SENSAKOVIC: One of the issues we are asking and, indeed, one of the items mentioned in here is just that. The initial approach was to report AIDS cases. That had to do with

a number of reasons, the first of which was they were initially reported before the blood test was available. Subsequent to that, we have continued reporting AIDS cases--

ASSEMBLYMAN OTLOWSKI: I think it is elementary. If you are going to fight a disease, you have to know where it is. As a matter of fact, I believe we were so successful with syphilis when we started to report it, track it, follow it up. Here, we are completely ignoring this.

DR. SENSAKOVIC: I really do not disagree with you. One of the things we are asking for is that we now start considering reporting positive tests, rather than just positive cases of AIDS, for tracking purposes.

ASSEMBLYMAN OTLOWSKI: In your opinion, why hasn't the Health Department-- This is probably the wrong question for you, Doctor. I will save that for the State Health Department.

DR. SENSAKOVIC: I really couldn't answer in that regard as to why it hasn't been done.

ASSEMBLYMAN OTLOWSKI: Let me ask them the question.

DR. SENSAKOVIC: I could speculate, but I don't think it would be fair to answer for them.

ASSEMBLYMAN OTLOWSKI: No, no, let me ask them the question.

ASSEMBLYMAN DEVERIN: But you do believe in tracking?

DR. SENSAKOVIC: I think it is time that we have to now start tracking.

ASSEMBLYMAN DEVERIN: Do you still track for venereal diseases?

DR. SENSAKOVIC: Well, a lot of arguments have been made to make a difference, one of which has been the fact that syphilis is a treatable, curable disease, but I am not sure that that argument holds any longer. I think now that we are seeing heterosexual transmission of the disease and the increasing problems with pediatric infections with the HIV virus, we are going to have to deal with the real issue. In

order to get a handle on it, we are going to have to know all positive cases, and we are going to have to try to break the chain of transmission of those cases.

ASSEMBLYMAN DEVERIN: Who they have been in contact with.

DR. SENSAKOVIC: The only way that can be done is with some system of tracking positive HIV.

ASSEMBLYMAN OTLOWSKI: Doctor, you know, there is a flight of common sense here. If syphilis is curable and it is still reportable, and a disease that is not curable is not reportable-- My God, where is all common sense? (no response) You don't want to answer that question, Doctor?

DR. SENSAKOVIC: I can't answer that question. I did not develop the policy.

ASSEMBLYMAN COLBURN: Okay. Thanks a lot.

DR. SENSAKOVIC: Thank you very much.

ASSEMBLYMAN COLBURN: We will now have Dr. Michalski, from METPATH. He is from a lab, so maybe he can enlighten us about some of these things. Yours, I think, is one of the accredited testing labs in New Jersey for this, is it not?.

**D R. F R A N K M I C H A L S K I:** Yes, it is. I want to thank you for giving me the opportunity to come down to talk to the Committee members.

I am Dr. Frank Michalski. I direct the Diagnostic Virology Lab at METPATH. It is one of the large commercial diagnostic laboratories in the United States. It happens to be located in Teterboro, New Jersey. I was also a member of this committee -- the Medical Society Task Force on AIDS. Many of the things I really wanted to say are contained in the booklet that John Sensakovic gave out to you. So I just want to make a few remarks as far as what goes on in a diagnostic lab, to give you some information there. If you have any questions, you can ask me about that.

Specimens are sent to us by physicians. The physician gives a code to his specimen when it comes into our laboratory. In our Specimen Accession Office, they give a six-digit computer number to the specimen, and it is sent to our lab with no name on it. In our laboratory, we then do the tests, and the common test for AIDS is the antibody test by the Eliza (phonetic spelling), and then a confirmatory test by the western blot. We do the Eliza test, and if it is positive the first time -- or I should say reactive -- then it is repeated in duplicate. If one or two of those are reactive, it is considered repeatedly reactive.

Now, this Eliza test is a very good test. It has a tremendously high sensitivity and specificity. But in a population where we do not know the prevalence because the-- We know nothing about the patient. We only have numbers, as far as for testing, so we do not know the type of population we are getting this from. In a low prevalence population, even with good sensitivity and specificity, there is a possibility of some slight error in this test.

So, to confirm this, what we do is use the western blot test, which is another antibody test a little bit more specific. Then if a patient comes down with both Eliza repeated reactive and western blot positive, it is reported out.

Now, this is all reported to the physicians. The physicians are the ones who have the duty to do the pretest counseling and the post-test counseling of the patient.

ASSEMBLYMAN COLBURN: And the reporting of a result to the Health Department, under their current regulation.

DR. MICHALSKI: Yes. Because of confidentiality, there would be no way in the world we could report it to the Health Department.

ASSEMBLYMAN COLBURN: Well, if you report it positive, there might be duplicative reports--

DR. MICHALSKI: Exactly.

ASSEMBLYMAN COLBURN: --from different sources, of course. Do you do it by titer? Is it done by titer, any of this? In other words, the degree of positivity.

DR. MICHALSKI: No. It is done by an optical density end point, using controls.

ASSEMBLYMAN COLBURN: Okay. So, you don't get dilutions with that or anything?

DR. MICHALSKI: No. In our test, we use a dilution of one to 21 of the patient's serum.

ASSEMBLYMAN COLBURN: Let me think, there was something else. Oh, I can't think of it. Any questions?

ASSEMBLYMAN DEVERIN: Yes. If someone goes to a doctor and he has a blood test taken and they send it to you for an AIDS test, you only have a computer number? You have no idea who the patient is?

DR. MICHALSKI: None.

ASSEMBLYMAN DEVERIN: No idea what is background is?

DR. MICHALSKI: Nothing.

ASSEMBLYMAN DEVERIN: If someone goes to a doctor and he has a different social disease -- syphilis or gonorrhea -- and his blood is sent to you for a test, does that come with a number, too, or a name?

DR. MICHALSKI: No, that comes with a name.

ASSEMBLYMAN DEVERIN: So you know it is from a certain area or a certain type or a certain background?

DR. MICHALSKI: Yes.

ASSEMBLYMAN COLBURN: So this is treated differently than the other serological tests?

DR. MICHALSKI: This is treated completely differently.

ASSEMBLYMAN DEVERIN: Wouldn't we be better off if treated them both the same?

ASSEMBLYMAN COLBURN: Well, there are different points of view on that, so--

DR. MICHALSKI: There are very many different points of view. I think we have to maintain confidentiality. That is very important in the area of HIV.

ASSEMBLYMAN OTLOWSKI: Doctor, why do you say we have to maintain confidentiality of a disease that is so threatening, and that needs the attention of the entire panoply of government? Why do you say there has to be confidentiality? I don't understand that.

DR. MICHALSKI: Perhaps there are other experts you might want to ask that of. But as far as my opinion -- and I can't give you the opinion of the company--

ASSEMBLYMAN DEVERIN: But you said--

DR. MICHALSKI: My own opinion is that the connotations of the disease in the beginning were that anyone-- You don't want that information to be given out to anyone but the person who should know what is going on -- the doctor and the person.

ASSEMBLYMAN OTLOWSKI: Doctor, I don't know of any disease that is pleasant to have. The truth of the matter is, what makes this disease so different that it has to be hidden; that it has to be cloaked with secrecy? What is the difference with this disease that makes it so taboo, in your opinion, if you have an opinion? If you don't have an opinion, I am not going to press on.

DR. MICHALSKI: I think John deferred on that, and I think I would probably like to defer on that, also.

ASSEMBLYMAN COLBURN: Well, let me-- I will be a witness for a second. A tradition of physicians has been that what a patient has in the form of any disease, is really between the physician and the patient. There have been a lot of assaults on that. One of the first ones that I remember was third-party pay, because you wind up having to fill out an insurance form, and you say something about what was-- Quite honestly, on many third-party forms, I put down virus

infection, or some term that the person in the insurance office might have some trouble with, because a lot of those people are co-workers of the person you are reporting on. So, confidentiality to the medical profession is really important, as an overall concept.

Now, if we are talking about a special situation where society is totally threatened with decimation, you know, then perhaps you would have to change your attitude. But I am not ready to change mine just yet.

ASSEMBLYMAN OTLOWSKI: Doctor, I have no argument with the confidentiality -- that that concept. I have no argument with that. That ceases -- that confidentiality ceases -- when a greater public force is involved.

ASSEMBLYMAN COLBURN: I know what you mean.

ASSEMBLYMAN OTLOWSKI: And I think that is the question here.

ASSEMBLYMAN COLBURN: Yes, it is.

ASSEMBLYMAN OTLOWSKI: It seems to me that sooner or later we are going to have to grapple with it.

ASSEMBLYMAN COLBURN: Well, that may well be. That is one reason we're here.

ASSEMBLYMAN OTLOWSKI: As a matter of fact, I am not here to embarrass you, Doctor, or to-- I think -- and I am making it my own opinion -- we are making a terrible mistake, when you try to treat something like this with secrecy; a disease that undoubtedly is contagious under certain circumstances; a disease, to quote my good friend, the Doctor and the Chairman, that could be decimating, you know, if it is ignored and if it is not handled properly.

So, you know, I just think that something like this that we are doing now, is the time to hash over these questions. That is why I am so persistent in asking them.

ASSEMBLYMAN DEVERIN: You know -- the same thing for both doctors -- when Mrs. Coye talked about the 29,000-- I

listened to the Federal Task Force last night, and the doctor there thinks we ought to test every single newborn baby. Now, if a test comes to you with a number, whether you find it positive or not positive-- If it comes to you with a name and a background, if you know that the mother was an IV drug user, it makes a different result from the test than if it was just 29,000 mothers who were tested, or 29,000 babies who were tested.

DR. MICHALSKI: Yes, it sure does.

ASSEMBLYMAN DEVERIN: That is carrying confidentiality too far.

ASSEMBLYMAN COLBURN: Yeah, but the result goes back to the physician who ordered it. The result goes back to the treating place, or the physician. Somebody finds out. It is just that the lab does not know.

ASSEMBLYMAN DEVERIN: Yeah, but do we do the same follow-up with that person as we do with someone who-- For instance--

ASSEMBLYMAN COLBURN: Do you mean with syphilis?

ASSEMBLYMAN DEVERIN: Yeah.

ASSEMBLYMAN COLBURN: Not necessarily.

ASSEMBLYMAN DEVERIN: I know if someone has syphilis-- I know a person, a kid who used to work for the Democratic party here, who worked for the Health Department after he left. His job was to go around and knock on a door, and say, "Hey, your partner has gonorrhea," or syphilis, "and you ought to be tested." Now, I am not sure that that is a great--

ASSEMBLYMAN COLBURN: I think what both you and Mr. Otlowski are asking, in effect, is whether this confidentiality principle stands in the way of the management of the problem, isn't it?

ASSEMBLYMAN DEVERIN: Right.

ASSEMBLYMAN OTLOWSKI: That's right.

ASSEMBLYMAN COLBURN: We have to constantly rethink those questions as knowledge is changing about this disease.

Thank you very much.

DR. MICHALSKI: Thank you.

ASSEMBLYMAN COLBURN: The next witness will be Mr. Gene Brunner. Are you in the room somewhere, Mr. Brunner? (affirmative response from audience) Oh, come on up. Gene Brunner, Coordinator, HIV Counseling and Testing Services, Atlantic City Health Department. Do I have that right?

**E U G E N E B R U N N E R:** That is correct.

ASSEMBLYMAN COLBURN: You must know Ray, over here, don't you -- Ray Cox, Legislative Aide to Assemblyman Kline?

**R A Y M O N D W. C O X:** We've never met.

MR. BRUNNER: No.

ASSEMBLYMAN COLBURN: Okay.

MR. BRUNNER: My name is Gene Brunner. I am the Coordinator of HIV Counseling and Testing Services for the Atlantic City Health Department. I am here today to give testimony on behalf of myself and James L. Budd, who is the Health Officer for Atlantic City, who is unable to be present today. I want to thank Chairman Colburn and the members of the Committee for having us today.

The Atlantic City Health Department is currently the regional counseling and testing site for Atlantic, Cape May, Cumberland, Gloucester, and Salem Counties. We are one of the four original counseling and testing sites established in New Jersey through the New Jersey State Health Department and the Centers for Disease Control. Under the old method of operation, designed to prevent contamination of the nation's blood supply, we tested approximately 500 persons a year. It soon became apparent that this focus was too narrow. We decided to do extensive outreach with our program. Specifically, we now place counselors in public health departments and private health care agencies in our region.

Only through an outreach system such as this has HIV counseling and testing been made cost-effective and accessible to the general populace of most of southern New Jersey.

We are now screening 625 persons per month because of outreach capabilities, in contrast to 550 persons per year with only one location. This has made a tremendous impact in reducing the unit cost per test. Our present unit cost is $36.85 per test, as compared with $300 per test without outreach services. We attribute our ability to provide reasonably cost-effective counseling and testing services to the fact that we have aggressively interacted with other health care providers, instead of acting independently.

Whereas some health care providers are reluctant to become involved with HIV counseling and testing, we have found that our services are not only accepted, but welcomed by the public. We attribute this to the confidentiality of our record-keeping system and to the establishment of several satellite testing sites throughout southern New Jersey. In order to do this, any agency charged with implementing HIV counseling and testing must be financially solvent, so that patients and patient records are protected if funding lapses occur.

Furthermore, funding of public health departments as regional test sites has importance in terms of data gathering and assistance in reporting requirements. Management of communicable diseases has been traditionally performed in a competent fashion by public health departments, and not by other health care providers now seeking funding for counseling and testing. The funding of individual program areas such as family planning, tuberculosis control, and sexually transmitted diseases, we feel, is not as cost-effective or centralized as is the funding of a health department for an expansive counseling and testing program in conjunction with other providers.

Finally, in order to best serve community-based organizations, minority groups affected by AIDS, and the general public, HIV counseling and testing must be flexible and responsive to the needs of those populations.

Thank you.

ASSEMBLYMAN COLBURN: Thank you. One thing comes to mind, and that is -- and you brought it up, it's interesting -- what happens to the records if an agency loses funding? In addition to that, what happens to the records while they are operating? We are not going to answer that this afternoon, but I think that was a good question you brought up. Does anyone want to ask any questions? (no response) Thanks a lot.

MR. BRUNNER: Thank you.

ASSEMBLYMAN COLBURN: I have gotten myself a little bit out of order here. I really meant to call Mary Boland, Director, Children's Hospital of New Jersey AIDS Program. Are you still here, Mary?

**M A R Y G. B O L A N D:** I'm here.

ASSEMBLYMAN COLBURN: Come on up. I got a little bit out of order. Good afternoon.

MS. BOLAND: Good afternoon.

ASSEMBLYMAN COLBURN: Are you going to have those passed around to us, I hope?

MS. BOLAND: Yes. Here are a few. (referring to copies of written statement)

I am pleased to be here, and also to talk to you about children with AIDS. I am the Director of the AIDS Program at Children's Hospital of New Jersey, which is located in Newark. The first children with pediatric AIDS were identified at Children's Hospital in 1982. Within a short time, it became obvious to us that the hospital was in the epicenter of the AIDS epidemic in New Jersey. While designated as a tertiary level facility, Children's is a 129-bed institution that provides care to large numbers of children from the Newark

community. As the diagnosis of AIDS and HIV infection began to account for increasing numbers of patients and the characteristics of the population at risk for, and suffering from HIV infection became clear, we realized that the medical diagnosis had significant implications for the health care delivery system. In addition, there were social implications for both the affected families and the overall community.

However, our primary goal was, and is, to assure delivery of competent and compassionate health care to children and their families. Thus, we utilize a family-focused approach to care. To meet these goals, or this goal, a staff of physicians, nurses, and social workers provide care for the child from the time of testing and diagnosis throughout the course of the illness, through the time of the child's death. We also attempt to offer bereavement services to the family after the death of the child. We provide care both in the hospital as well as in the home, and utilize a case management approach.

Parents are considered to be an integral part of our team, and are actively involved and participate in decision-making at all stages of the child's illness. Because we are located at Children's Hospital, the family has access to a full range of medical sub-specialists, ancillary services, as well as an Early Intervention Program, and is soon to be operating day-care programs sponsored by Babyland in Newark. Each family is also helped to find a primary physician in the community, if they do not have one.

As many of our children and families are under the supervision of child protective services -- DYFS -- a formal relationship has also been developed to optimize collaboration between human services and health care delivery. CHAP also works closely with community-based services that are made available to families, including community nursing, hospice care, home care vendors, etc.

Since 1984, CHAP has worked with 162 families of children with HIV infection. Five of those families have had more than one child infected with the disease. About 45% or 46% of our children have been male; about 54% female. Sixty percent of our population is black; 20% is Hispanic; 20% is white. We have served children from throughout the State. However, the majority of our children have come from Essex County, from Union County, and from Hudson County. In addition, we have also provided care to 11 children from New York and one child from Pennsylvania.

The source of payment for our population is Medicaid for 82% of the children; private insurance for approximately 11%; and 7% of the children have no health care insurance.

Ninety percent of our children -- as Dr. Coye demonstrated from the State's statistics -- acquire HIV infection from an infected mother. Of our women who are infected, 55% are intravenous drug users. Forty percent of the mothers identify their risk factor as a sexual partner at risk for, or infected with AIDS. So what that means is, of the women who have children, half of them are drug users, but over 40% of them now acquire their disease through heterosexual transmission, usually from a partner who had no idea he was infected. Many times, the child is the first case in the family. The child comes to us. We diagnose the child and, as a result, we find out that the mother, and often the father, are infected.

The number of patients increases each year, with one child being diagnosed every week. In 1985, the progam had 95 visits for outpatient care -- the first year we kept records. In 1988, we had 1275 visits for outpatient services for children with HIV. Hospitalization occurs for the symptomatic child an average of twice a year, with an average length of stay of 29 days, with a range, though, of from one day to 243 days. Our largest hospitalization was one child who stayed

with us for 375 days. Our institution had 150 hospitalizations for children with AIDS in 1988.

We are responding to an increasing demand for our services. Our philosophy also works very closely at including families in decision-making about their child. We work with them to help them to acquire the knowledge and the services they need to cope with the illness.

The Children's Hospital AIDS Program was formalized in January of 1987, so we are a new program, approximately two years old. We are completely funded by a variety of different grants, a combination of State funding, as well as Federal funding. Our program is now providing several components. We provide comprehensive medical care, including antiviral therapy. We are one of 13 centers in the country that has been funded to do research on antiviral drugs in children. However, we are the only center in the State, and we are the only site through which children in the State can receive care. We are also involved in clinical research. We do outreach education, both to providers of care, as well as to community groups such as schools. We are also very much involved in advocacy, and work closely with a variety of community institutions.

To try to demonstrate to you the complexity of services required by a family, we have developed a case study, which is included in my written statement, but which I will not read. This was taken from a real life case of a child who received services at our program. By reviewing that, I think you will get a sense of the complexity of the HIV infection, how it impacts on the generations, as well as the variety of service delivery systems within the State.

Our challenge now, I think, is to collaborate to prevent fragmentation and duplication of services; to continue to develop programs outside of the immediate Newark area, so that children have access to competent and comprehensive care. In cooperation with the Department of Health, we have begun to

develop a statewide network of providers, who will work collaboratively, not only with Children's Hospital and the Department of Health, but also with the Division of Youth and Family Services, to provide care to the children and families.

The main concern of programs like ours that provide direct services, is that our support is provided 100% by grants, and that the infrastructure required to provide the kinds of community-based care that we deliver does not exist within the health care system, but particularly within the inner city. The existing reimbursement system does not compensate for the services provided to families. In addition, many times those services are nonexistent. By default, the Children's Hospital Program will try to plug those holes in the net.

To give you an example, Newark has no community-based hospice within the city for adults or for children. Suburban programs will not serve areas of the city. So, if a parent wishes a child to die at home, and we know the child is in the terminal stages, we have nothing left to offer them. CHAP provides that support to the family. So it is one additional service that our program provies, although we are not reimbursed for it; we are not funded for it.

Another example is: If a child wants to go to school -- and I think this alludes to many of the confidentiality aspects that were talked about earlier -- while the State is mandated to provide education for children with HIV infection, the reality of entry is very difficult for children. So again, one of our staff people will have to help the parent to get services which are available to them, while attempting to protect their confidentiality, so if the family has older children in the school system, those children are not stigmatized because their younger sibling has been identified as having HIV. As a consequence of our daily contact with the children and their families, we realize the toll of

stigmatization and the lack of available services. We have begun to address the issues of accessibility to a continuum of community-based services, and policy development to assure that those services can be developed and funded.

In 1986, the Pediatric AIDS Advisory Committee was formed at the request of the Department of Health. The purpose was to identify issues and concerns related to AIDS. The group is composed of individuals and organizations concerned with the issue. As the problem has worsened, the committee has begun to focus on the maternal, as well as the pediatric and adolescent concerns. Our concern is that there continues to be major service delivery gaps for women and for children. Programing needs to begin to focus on the pregnant woman or the mother in relationship to her child.

One of our concerns about women who are infected, is that while many services are available for a woman who is pregnant or considering pregnancy, for the HIV infected woman who is not considering having children, it is very difficult for her to get health care services that are directed to her needs, often as a mother.

The AIDS Advisory Committee has been asked by Dr. Coye to prepare a report on HIV infection in women, children, and adolescents. We will be submitting the final report to the Commissioner in late spring of this year.

In conclusion, New Jersey has had success in developing programs that provide health care to children, recruitment of foster parents, regulation to assure that children attend school, etc. However, we are in the early stage of mobilization to the epidemic and have yet to feel its impact. There remains a need to develop a statewide plan for dealing with the epidemic, as it is clear that significant numbers of women, children, and adolescents will continue to be infected. These families will strain already overutilized and underfunded services.

Thank you.

ASSEMBLYMAN COLBURN: Thank you. Any questions? Mrs. Ogden?

ASSEMBLYWOMAN OGDEN: I have a question. In reading through the case study here of the child being in and out of the hospital almost constantly from nine months to three years, I think, do you think that if there were a hospice program set up that it could have accommodated the reason she came to the hospital repeatedly?

MS. BOLAND: Well, this child came to the hospital for acute medical problems early on in her illness, but as time went on to have this residential service, it may not necessarily have needed to be hospice, as much as support or step-down medical care-- That would have been helpful, yes.

ASSEMBLYWOMAN OGDEN: Well, I didn't really mean hospice in the sense of a terminal illness, but more outpatient, I guess, was what I was thinking of.

MS. BOLAND: Well, it is very difficult when you look at AIDS, because as children get sick, they tend to get very sick. We feel that with comprehensive services, though, you do make a dent in terms of hospitalization. Our program, although we take care of 162 children right now, last year had 80 children accounting for our hospitalization. So it was clear that close to half of our children were actually never hospitalized. We think that that probably demonstrates the impact of having coordinated care for them, but the numbers are still large enough so that you will need significant hospitalization for children.

ASSEMBLYMAN COLBURN: Thank you. Gentlemen, anything?

ASSEMBLYMAN DEVERIN: What is the age range of the children you take care of?

MS. BOLAND: We take care of children anywhere from birth up until 17 years, which is the age of our oldest child. The majority of children, though, are under the age of six. So we're looking at a population, essentially, of preschoolers.

We do recognize, though, that with the long incubation period, we are seeing children who were infected at birth, being diagnosed at 10 and 11 years of age. So it is clear that some children can live for a long period of time with the infection. It is not necessarily, you know, a very short life span for them.

ASSEMBLYMAN DEVERIN: You are the only hospital in the whole State of this nature?

MS. BOLAND: At this point, yes. We are working closely with Jersey City and St. Joseph's to develop centers in those areas.

ASSEMBLYMAN DEVERIN: There are none in the southern end of the State?

MS. BOLAND: None at this point.

ASSEMBLYMAN COLBURN: Okay. Thank you very much.

Ray, do you want to step up here for a minute? Ray Cox, representing Edward Kline, the Assemblyman, now in Florida.

MR. COX: Now in Florida. Doctor, we appreciate the opportunity of being able to have our say at this Committee hearing. The Assemblyman has a statement that he prepared prior to the end of last year, which we have been using, and I would like to read from that. Before I do, I just want to note that the last couple of days have been one of those instances in your life when you soar to pinnacles, and then you drop to the bottomless pit with depression. When the phone started ringing the other day, all the numbers of people said, "We want to be included in that Advisory Council that the bill is calling for."

ASSEMBLYMAN COLBURN: Everybody in the room.

MR. COX: I said, "Gee whiz, what did we do right here?" because up until this point-- We have had legislation in -- some 14 pieces of legislation -- since 1985.

ASSEMBLYMAN COLBURN: I have been looking at it.

MR. COX: Whenever we were fortunate enough to have a piece of legislation come before a committee, when the elevator door opened, people were lined up to say, "We object to your bill." We just told them to take a number and stand in line. Now, all of a sudden, you know, it is the reverse.

The down side is to hear the disturbing news that the good Dr. Coye has given us about the increase in the numbers of cases, particularly with children. It is kind of frustrating because all of the legislation that we have introduced addressed these very same issues, but has fallen on deaf ears.

I was gratified this afternoon to get answers to our questions in a letter we sent to Dr. Coye last year. Finally, in the information that was given to us, the majority of those questions were answered, to a degree. There are still some problems, but we will get together with her later on those.

I would also like to acknowledge Bob Hummel's contribution in the latest issue of the "Governing" magazine, where he states that if we sit back and do nothing, every other disease will look minuscule compared with it, meaning AIDS. Heart disease, Alzheimer's disease, and cancer are not transmittable, true. In our conversations with many people in the health field, AIDS is just magnifying all of the problems in the existing health care system. With any problem you can think of, AIDS is making it worse.

Having said that, and gotten it off of my chest, so to speak--

ASSEMBLYMAN COLBURN: Relatively diplomatically stated.

MR. COX: Thank you.

ASSEMBLYMAN COLBURN: Relatively.

MR. COX: Assemblyman Kline would like me to read the following statement.

ASSEMBLYMAN COLBURN: There is no date on this. Is this what he has been reading for some years now? (laughter)

MR. COX: Yes.

ASSEMBLYMAN COLBURN: Oh, okay, just asking. Does he change with the changing situations at all?

MR. COX: We try, from time to time, when the information becomes available to us, to--

ASSEMBLYMAN COLBURN: This is such a rapidly evolving field. I know you have been following it very closely.

MR. COX: Within the last year, it has just grown by leaps and bounds.

"As an elected official trying to deal with the AIDS epidemic, I perceive myself as an advocate for not only the voters in my district, but as an advocate for the general public throughout the State of New Jersey. Any legislation I introduce or support, I do so with the knowledge that it is 'draft' legislation, and I do so with the understanding and willingness to amend the draft, if necessary, to be consistent with reality. The major thrust of any legislation that I introduce, co-sponsor, or support, is to enhance the quality of life for the citizens and the children, both present and future, in the State of New Jersey.

"In this day and age of technology and general enlightenment, I find it incomprehensible that we continue to perpetuate the stupid, uneducated ignorance that surrounds us as we try to deal with this disease which we commonly call AIDS. It's time to scale the wall of fear and remove the social stigmata with facts.

"The growing threat of acquired immune deficiency syndrome/HIV -- AIDS -- has many New Jerseyans, and every state across America frightened. Although scientists are working on this problem, so far there is no cure or vaccination for this deadly menace. Acquired immune definciency syndrome destroys the body's ability to combat this disease. For a victim that is HIV positive, even an infection from a common cold could spell death. The numbers are taking an alarming direction, with a 39% jump in the number of reported cases in New Jersey

over the last six months." Remember, this is 1988. "According to the State Department of Health, the number of AIDS cases in New Jersey has already scaled 4531 and, as of June 27, New Jersey ranks fourth in the nation, with only New York, California, and Florida having more cases. New Jersey also ranks second in the nation with reported pediatric cases. On a national level, 57,024 are infected. World-wide, approximately five million people have unknowingly been infected. Deaths on a statewide level have reached 60% of those infected. Nationally, 179,000 will be dead by 1991." I believe that number is totally incorrect, at this point. "Total expenditures to date for the State of New Jersey in dealing with the acquired immune deficiency syndrome disease are $6,458,000,000, and medical costs for 1990 are expected to increase by $20.4 million to $22.6 million."

ASSEMBLYMAN COLBURN: Ray, may I stop you for just a minute?

MR. COX: Sure you can.

ASSEMBLYMAN COLBURN: That was $6,458,000, wasn't it? Did you say, "billion," or did I miss that?

MR. COX: I said, "billion," I'm sorry.

ASSEMBLYMAN COLBURN: Is that "million?"

MR. COX: Million, right.

ASSEMBLYMAN COLBURN: Okay.

MR. COX: Thank you. "It is also commendable to note the various channels of communication that have been pursued publicly, in order to better deal with the reality of the AIDS situation. We in the New Jersey Legislature would like to congratulate the New Jersey Cable Television Association, which has recently tried to keep the communication lines open with their program, 'AIDS: Everything You and Your Family Need to Know -- But Were Afraid to Ask.'" If you recall, this aired before the end of last year.

"Likewise, the Community Services Department of the New Jersey State AFL-CIO recently sponsored an informative conference on AIDS in the Workplace, and has put into effect the, 'Responding to AIDS: Ten Principles for the Workplace,' the first principle of which states: 'People with AIDS or human immunodeficiency virus infection are entitled to the same rights and opportunities as people with other serious life-threatening illnesses.'

"The timely words of encouragement from a young teen-age AIDS patient named Ryan White, encouragement based on his own sad experience, given to those in the teaching profession: 'Teachers can play an important role in helping an AIDS student to be accepted and treated as normal as possible, by teaching the facts, not the myths, such as, AIDS cannot be transmitted by sneezing, coughing, spitting, kissing, handshaking, or by the common use of restrooms, tools, eating utensils, or telephones.' Ryan says: 'By proper education, AIDS can be a disease, not a dirty word.' No one could have said it better.

"I was recently questioned by a local newspaper reporter about, the 'scattershot approach' to AIDS legislation which I have introduced. My approach is not to add to the hysteria, not to ostracize, not to point fingers, but to try to really deal with the problem; to dispel the myths and misinformation which prevails. As to my compassion for those afflicted with AIDS, I answered: 'I have compassion for those afflicted at this moment, but I also have concern for the future generations of this nation.'

"As a State legislator, it is extremely difficult to create legislation which would offer a solution to every phase of the AIDS problem. However, I believe detection, plus education for those infected, as well as those not yet infected, will lead to future prevention, and children such as Ryan White, or any child in our future, will not have to live

with the rejection associated with AIDS, and to live their young lives with the knowledge that they are going to die before they have had the chance to live.

"Now is the time to open the channels of communication, and pinpoint the high risk AIDS categories in order to be better prepared to deal with the reality. How can we effectively reach out and help the people who are currently AIDS infected? How can we give them information and direction, if we do not even know who is infected? Unfortunately, today, the people who are infected with the AIDS or HIV infection are faced with the connotation or pervasive attitude that they no longer belong in society and the human race because of the social stigmata associated with AIDS. The only comfort which can be offered is our understanding of the symptoms and our words of encouragement.

"The New Jersey State Department of Health persists, dogmatically, to oppose any and every source of legislation that has been introduced to date. The only legislation the Department of Health favors, endorses, and supports, is legislation which is asking for money that is needed, so they say, in order to carry the educational campaign forward. But they persistently neglect to tell us, who and how many? Since the citizens/taxpayers of our State foot the bill for this education, are they not entitled to know who and how many? We have, to this date, legislatively spent $6,458,000 of taxpayer dollars, because we have been told this is what is needed. Under any other set of circumstances, these kinds of appropriations would not have been made without all of the vital statistics and cold hard facts to support such appropriations.

"Unfortunately, the cost to the government and the cities of this State and nation in the future is going to be astronomical. We cannot even project and plan for estimated debts, because of our continued cloak of secrecy.

"We must know who and how many now! We will be held morally accountable to the next generation of AIDS victims.

"There are many, many people who, while infected, are displaying unimaginable courage and fortitude in their making public that they have been diagnosed HIV positive, and in doing so they expose themselves to ridicule and are stigmatized as social outcasts. They have no control over their illness, and yet they are willing to go public, making known their condition and offering themselves as human guinea pigs, in the hope that they may be instrumental in prolonging someone else's life or ultimately be the vehicle for a cure. What a terrible price to pay during the last days of your life."

That is the statement that Assemblyman Kline has been making for the last eight or nine months.

It was interesting to note--

ASSEMBLYMAN DEVERIN: Don't we have a bill, Mr. Chairman?

ASSEMBLYMAN COLBURN: Yeah. For today, do you mean?

ASSEMBLYMAN DEVERIN: I don't want to expedite it, but--

ASSEMBLYMAN COLBURN: No, no.

ASSEMBLYMAN DEVERIN: --if we have a bill, I would think we ought--

ASSEMBLYMAN COLBURN: At three o'clock, I am going to break for that.

ASSEMBLYMAN DEVERIN: Okay.

MR. COX: I also want to note that in "Governing" magazine, February 1988, a Dr. Deborah Cotton (phonetic spelling), who is at Beth Israel Hospital, has, I think, said it quite clearly; that AIDS has a fair chance in debate over health care priorities, and you could even make a case -- make an argument -- for spending less on AZT, which costs $600 to $800 per month per patient, because it only prolongs life, and cannot cure. Why not spend more money on prevention? Those

kinds of decisions will have to be made by legislators, not health care providers. To make them fairly, the lawmakers need to educate themselves more about the AIDS situation in their own states.

That is what we have been endeavoring to do for the last three years. We have been in communication, I guess, with just about every state in the nation. The last one was the comprehensive package that Florida introduced. When we digested that package of bills, we were happy to note that all of the AIDS legislation that we have introduced, was incorporated into that comprehensive package in Florida.

I was a little concerned when we reviewed the budget of the Department of Health and found that there was a 3.3% reduction. I was particularly concerned, and I am sure there are other states across the nation that are equally concerned, as to how, in the face of demands for increased financing, we were able to effect that kind of a budgetary cut. If the Health Department of New Jersey somehow has the ability to get more bang for its buck, I know we would like to know about it. I'm sure the other states in the nation would love to know about it, as well.

By way of closing, it has been brought to my attention that there are some morale problems in the AIDS Division due to differences between the various employees. I would hope that no effort to intimidate any individuals will be made due to these differences. Given the serious nature of the AIDS problem and the sensitive information the AIDS Division deals with, I would hope that no transfers in or out of the AIDS Division will be made, without the consent of the employees involved.

That is about the extent of it.

ASSEMBLYMAN COLBURN: Thank you, Ray. Does anyone have a question of Mr. Cox? (no response) Ray, is it true that the first bill that Assemblyman Kline introduced-- Was it

the one that would mandate premarital testing? Was that the first bill?

MR. COX: That was the first one, yes.

ASSEMBLYMAN COLBURN: I think that is what steered me clear of his bills in general, to be honest with you. (laughter) So, from that point on, I was sort of mulling over in my mind what attitude I ought to take toward you folks. Now I find that you have studied this a great deal, and that we all need to do that. I think maybe we are back on a little better track, but that first bill, I have to confess-- I declined co-sponsorship of it, as you may recall.

MR. COX: Yes, I know, Doctor.

ASSEMBLYMAN COLBURN: So, if you will just pardon that little, almost an aside-- It was sort of a frontal attack, though, in a way. (laughter) Thanks a lot. Have a seat right over here again, will you please?

MR. COX: Thank you, Doctor.

ASSEMBLYMAN COLBURN: Let's see-- Mr. Sauerwein, from Atlantic County. You're representing the Atlantic County AIDS Task Force?

**R O D S A U E R W E I N:** That is correct.

ASSEMBLYMAN COLBURN: Are you representing any other group that is here today? I am confused about who is who.

MR. SAUERWEIN: Well, actually, I am with the Association for Retarded Citizens, Atlantic Inc.

ASSEMBLYMAN COLBURN: Okay.

MR. SAUERWEIN: But I am representing the Atlantic County AIDS Task Force, which is a coalition organization representing 25 social, medical, and human services agencies serving Atlantic County.

In the packet that is being passed around, is a list of the membership, as well as other information regarding the Task Force.

The Task Force was created nine months ago, and is dedicated to strengthening the community and addressing the issues of HIV infection, AIDS, and related problems.

Many of our member agencies are actively involved in education and service on a variety of social and health issues. It is the Task Force's intent to use existing programs and networks to educate Atlantic County regarding HIV, its prevention, and the needs of those already infected. Whatever we as a Task Force are able to accomplish, however, appears to be a drop in the bucket when compared to the ever-growing need for education of every person of every age in our county. We are aware that education must be reinforced many times and in many ways, if we hope to effectively change behavior and attitudes, as well as knowledge.

Atlantic County's need from the Legislature is a profound dedication to assisting our health and social service professionals in this major education process. We have found some legislators' approaches to be troublesome, however.

ASSEMBLYMAN OTLOWSKI: Only some?

MR. SAUERWEIN: Pardon?

ASSEMBLYMAN OTLOWSKI: Only some?

MR. SAUERWEIN: This is a consensus of 25 people.

The Assembly, for example, passed what has come to be referred to as the "sex abstinence" bill, despite opposition by the New Jersey Education Association, the New Jersey Department of Health, and many other community groups, including our Task Force in a letter to Senator Gormley. A copy of same is included with our written statement. It is our position that this type of approach on the part of the Legislature is not helpful. Our mutual goal should be to provide the greatest amount of information to the greatest number of people, not to restrict or censor information, or to provide misinformation, which is what the sex abstinence bill appears to do. We urgently need you to listen to the experts in health and

education, and thereby support those of us who serve on the front lines.

Equally important is our need for access to quality health care services for those infected with HIV. In southeast New Jersey, we have identified three main areas of immediate concern:

1) The shortage of infectious disease specialists, or doctors experienced in treating HIV infection and AIDS,

2) The total lack of pediatric medical services related to HIV,

3) The lack of access to clinical trials to help residents of southern New Jersey receive the benefits of promising experimental drugs.

The Atlantic County region has special concerns. The State Department of Health informs us that our county has the highest rate of AIDS cases in southern New Jersey, when adjusted for population. Our rate is twice as high as the next highest county -- Camden.

We need assistance in recruiting infectious disease specialists to southern New Jersey, developing specialized community-based medical services and facilities, and we need help in increasing access to the experimental drugs. Our Task Force has several specific suggestions towards this end, and more information has been given to you in our written testimony.

Thank you.

ASSEMBLYMAN COLBURN: Thank you. Mrs. Ogden?

ASSEMBLYWOMAN OGDEN: Yes. I am curious, since education and information are being stressed so much, are most of the schools, or all of the schools in Atlantic County providing a program?

MR. SAUERWEIN: To my knowledge, there are some, but I cannot tell you how many. As I say, I represent the Legislative Committee for the Task Force, which has a list of 25 agencies and organizations. I cannot honestly tell you how

much education is going on. We will have another speaker later from the South Jersey AIDS Alliance. I'm sure Michelle Brunetti will be able to answer your question.

ASSEMBLYMAN COLBURN: Gentlemen? (no response) Thanks very much.

MR. SAUERWEIN: Thank you.

ASSEMBLYMAN COLBURN: Jeffrey Bomser, representing The People with AIDS Coalition of New Jersey. I guess you are not the person Mr. Sauerwein referred to just now? Was he talking about a South Jersey--

**J E F F R E Y B O M S E R:** No.

ASSEMBLYMAN COLBURN: Okay. I want to get everybody straight here.

MR. BOMSER: My name is Jeffry Bomser. I am the President of The People with AIDS Coalition of New Jersey. One of the requirements for that position so far, is being a person with AIDS, which I am.

What I would like to address -- and I thank you gentle people for the opportunity-- AIDS isn't simply a topic of discussion to we who are PWAs, or those around us whom we consider PLWAs, which means "people living with AIDS," and in this day and age, that pretty much encompasses everybody. We are people; we are not various risk groups. We are individuals. I have already heard many times today -- I am getting a little bit used to it, but am nevertheless concerned-- I, as a PWA, am not a victim. PWAs, as a whole, are not victims, unless they choose to be. The term "victim," by definition, implies defeat. I, for one, am far from being defeated by this, or anything else.

We are sometimes patients. PWA is sometimes mistaken for "patients with AIDS." Only sometimes, hopefully very rarely, hopefully never, are we patients. What we are, are people with AIDS; people the key word, once again.

As President of the Coalition, there are a number of topics I would like to mention for your perusal. One of the main directions we are hoping the State will go, is in the increased use of community-based clinical trials. These offer the chance to expand the demographic and geographic reach of drug trials to all infected people. We would also like to see some steps taken, if and where possible, in prohibiting price gouging. The government must exercise full authority to allow infected people full access to all approved drugs and, in some cases, unapproved drugs.

There is a great need for increased funding to meet the long-term counseling needs of infected people, and to provide services for those suffering AIDS dementia. To expand AIDS education programs, particularly those directed to minorities, adolescents, prisoners, and other groups not adequately served, funding should be directed, once again, to community-based organizations. The addiction treatment programs for IV drug users must be available on demand. Hospice and other cost-effective alternative care delivery systems should be developed to meet the ongoing medical needs of infected people; increased training programs, the whole spectrum of AIDS care providers -- and this needs to be done yesterday, not in some future session. And maybe most important, or two of the most important--

I am not a strong advocate of any given therapy treatment, drug or otherwise, but AZT is a widely used one. It is depended upon by a great number of PWAs in this State as the sole treatment source. I have heard it mentioned that perhaps current PWAs should be allowed to die, so we can avoid new PWAs. I hope that was a single opinion. But, develop a permanent source of subsidy for AZT, so this treatment is available to all, including asymptomatics, who are ineligible for Medicaid.

The most important -- or again, close to most important -- is to strengthen anti-discrimination measures. Existing protection statutes should be aggressively enforced. Expanded protection is needed to prevent discrimination in the private sector. I heard a lot of talk about common sense, and why is it so secretive, and such. Until there is 100% anti-discrimination protection for people who are HIV positive or who have AIDS, people will go underground; will not go to our health care providers -- doctors and clinics -- and will seek alternative treatments, and you will have no handle on the AIDS problem in this State.

You mentioned about the marriage -- the premarital counseling.

ASSEMBLYMAN COLBURN: Testing was what I was talking about.

MR. BOMSER: Testing, right. I believe the one state that did that was Michigan. Within the year, their marriage licenses dropped 40%; Wisconsin, next-door, went up an equivalent amount. It may sound humorous, and in a sense it is, but that is what is going to happen. You are going to drive people to other states, which maybe to some people would be a solution. I hope not. Or, you are going to drive them even deeper underground.

The importance of these anti-discrimination laws and protections is, the earlier someone is tested, in my opinion, and in the Coalition's opinion, the better chance they have of maintaining health and quality of life for the longest time. The project from California, which is very verbal and very informed on various treatment options, states that the challenge isn't whether or not to take the test, but to determine how to learn one's antibody status and monitor immune health without -- a big word, "without" -- risking employment insurance or legal status. All too many people we meet every week at our Coaliton meetings, have already lost their jobs or

are being evicted from their apartments, and there is no recourse, because in current standing New Jersey law, you can be evicted for having a disorder like AIDS. There is no protection. Those people are not going to come forward and want non-confidential anything.

Another point, just for your consideration, is expanding the spending of funds for prophylactic treatment for people with AIDS. The medical profession, as a whole, generally works on a theory of sick care, not health care; saying, in effect, "Get sick, and we will help you to get better again." With something like HIV infection, if you stay healthy, then perhaps we wouldn't need the hospital stays and varied treatments. It is a strange situation that preventive medicine is so low on the list, when everyone is so concerned about infecting all of society and the costs of the health care system. A whole symptom observation approach, rather than having money for lab studies and blood tests, and staying healthy, I think have to be given a lot more consideration.

The Long Island Coalition had a sentence I wanted to read, which simply states: "There simply isn't another disease model which calls for withholding treatment until the illness advances to a life-threatening stage." Yet today, our hotlines remain deluged with calls from people throughout the nation, who are being refused treatment until some arbitrary level of illness is obtained. This is both absurd and increasingly unethical.

Medical centers, insurance companies, and medical professionals which still endorse such practices are living in 1986, and are doing their patients an enormous injustice. Again, this should be a case of a little more than common sense.

There are a couple of other points I would like to make, and I realize you have a three o'clock appointment following this. There is something else where I do not have an outline on how to do it, but I think it is imperative that it

is done. Utilize one of the strongest natural resources in this battle you have, and that is the PWAs themselves. All too often, PWAs are being treated as, you know, little puppy dogs. They are not being given direction where, through self-empowerment, they can help themselves and others. I know a hotline-- When I first started calling, when I was first diagnosed, I spoke to some not-all-that-knowledgeable professionals, and I was left as frightened and confused as before. The first time I had an opportunity to sit down with another PWA and see a thriving, surviving, living person, was the first time that hope and faith came into my life after diagnosis, that life could go on. It was not a death sentence. Before that, the media did a real good job of scaring me, and many others, into believing that it was a death sentence.

Again, just to have it in the record, I know there is a lot of fear on the part of different members of society. AIDS is not easy to catch. It has been mentioned a couple of times, but it cannot be mentioned enough. As an example, and I had to get permission to say this, I have been married for a number of years. I was married and with the same person for a while before I knew, and before we had a chance to practice any safe procedures for sex, a word that no one seems to be mentioning here today. My wife, for the fifth time, just got her test results back, and once again it has come back negative, thank whatever higher powers you believe in. But just as an individual example, it is not easy to catch. We have been living together for a long time. In her partners' group, the numbers run pretty much the same; people who have been together for a long time, in the same house, sharing all utensils and all forms of what I consider healthy sex. Not one case in her partners' group, as partners of HIV positive persons, has tested negative.

ASSEMBLYMAN COLBURN: Has tested positive?

MR. BOMSER: Positive, I'm sorry. Thank you.

ASSEMBLYMAN COLBURN: Okay.

MR. BOMSER: Again -- and I have a little star next to this -- the necessity for anti-discrimination protection. One thing the Coalition members asked me to mention -- and I know it is an oversight with most people-- We constantly hear the term, "innocent victims," referring to children. I like children, I believe, as much as anybody, and I do not think they are guilty of anything. The problem isn't with their title of being "innocent victims" -- those children who are HIV positive -- but the connotation that the rest of us are guilty, or something. If you happen to have personal problems with sexuality issues, or with intravenous drug abuse, that's fine. But I don't think you would say someone who smoked in the early '40s and '50s and got lung cancer, is guilty of having lung cancer. I don't think you would say a jogger who dies of a heart attack from overexerting himself is guilty of having a heart attack. Yet, we are constantly, daily, in press and media, being told that if we are not the innocent children victims, we are the other ones -- the guilty victims. That is not a very strong self-empowerment message.

That brings me to my last point, which is the need, we believe, to have publicly identified people with AIDS on almost all committees dealing with AIDS' decisions. It would be sort of ludicrous, similar to having a sickle-cell anemia committee on rights or medical treatment or whatever, and not considering having someone who is black or someone who is directly involved with sickle-cell anemia on that committee.

I thank you for the opportunity. I could go on forever with different little facts and figures. One thing I would like to say is, I am very proud and grateful for how much this State has done in this confrontation with AIDS. I battle with a lot of different aspects of it, but I go to different conventions in different parts of the country, and everyone is

quite impressed with what New Jersey is doing. I think that's wonderful.

The other side of it is, with a lot of things we are doing, we are not getting the information to the people who need to know it. I don't mean to point fingers. I won't even go into the specifics, but there are a lot of programs that are available, where money has already been spent, and it is six months to a year later when the actual people who need the information -- the PWAs themselves -- hear about this, that, or the other program. I think we need to increase not only doing it at this level, but getting it to the grass-roots organizations.

Thank you.

ASSEMBLYMAN COLBURN: Thank you.

ASSEMBLYMAN OTLOWSKI: Mr. Chairman?

ASSEMBLYMAN COLBURN: Yes, sir, Mr. Otlowski?

ASSEMBLYMAN OTLOWSKI: First of all, I would like to say this to you: I think you are a very unusual person. I think people like you make a great contribution to this cause we are dealing with here today. I am tremendously impressed by your honesty, and by your straightforwardness. As a matter of fact, in my opinion, it will be people like you who will be of tremendous help. You are to be commended for coming before this Committee to testify.

Now, we seem to have a little disagreement. Let me ask you this: If we continue to cover this in secrecy, aren't we going to be worse off? Isn't it going to take longer than if we deal with it openly? You're dealing with it openly and frankly, and that is very, very unusual -- for someone to deal with it the way you are dealing with it, so openly and so frankly and so honestly. But by doing that, as I said, you are performing a great public service.

What is it, in your opinion, that puts this so much undercover? All diseases were unpleasant at one time. People

didn't want to talk about them. The mentally ill were put in basements. The people who had tuberculosis in their families would never admit it. The people who had cancer didn't want to talk about it. As a matter of fact, everybody denied that they had it in their family. What is so different about this than those other diseases?

MR. BOMSER: Well, I can't speak for the other diseases. What I see on a daily basis is the depth of the stigma placed on having AIDS; the amount of misinformation. In this day of massive media, you are almost avalanched--

ASSEMBLYMAN OTLOWSKI: Excuse me. What makes you think that mass media information is so correct or so near to the truth? Do you think anyone pays attention to the mass media?

MR. BOMSER: I would like to think that it is there for a reason, but I am not here to defend the mass media. I do know that I am very public with it. I happen to have the kind of personality -- I guess it is called a "big mouth" -- where, you know, I'll handle how society chooses to treat me. I have been met mostly with love, and a little bit of discomfort and hate. One of the detriments of my going public was that I was fired from my job. There are no laws in this State that say I can't be fired from my job. I can handle that as an individual. As an advocate for other PWAs, and as President of The People with AIDS Coalition--

ASSEMBLYMAN OTLOWSKI: So, what you're saying is that we are not ready to be as open as, for instance, I am hoping we would be. Is that what you're saying?

MR. BOMSER: Well, if you will pass more laws against discrimination, we can have more discussions about--

ASSEMBLYMAN OTLOWSKI: Well, wouldn't more laws just screw up the whole thing?

MR. BOMSER: No, not at all; absolutely not. That is a great reason, you know, not to get into doing it. But, if it

is no big deal, and it is, like, for the sake of society, then pass anti-discrimination laws and more people will come forward and be willing to share, and it will be more of a partnership than adversaries.

ASSEMBLYMAN OTLOWSKI: Mr. Chairman, through you, I just want to say again that I am tremendously impressed by your straightforwardness and your frankness. As a matter of fact, it takes a special person, and in my book you are a special person. I just wanted you to know that.

MR. BOMSER: Thank you.

ASSEMBLYMAN COLBURN: Thanks a lot.

I think we are going to adjourn the public hearing -- for a few minutes, I hope -- to act on a Committee substitute measure we have.

**(RECESS)**

**AFTER RECESS:**

ASSEMBLYMAN COLBURN: The next person to testify will be Dr. George Perez, Director of Virology at St. Michael's Medical Center, a division of Cathedral Healthcare System. Good afternoon, or good evening, or something.

**G E O R G E P E R E Z, M.D.:** Good afternoon, Mr. Chairman. Thank you for the chance to testify here in front of the Committee. It has been gratifying to hear some of the other people going before me testifying as well. I think nothing but good can come from such a public hearing.

I am Dr. George Perez. I am the Director of Virology Services at St. Michael's Medical Center, which is part of the Cathedral Healthcare System. I am going to be testifying on behalf of the Cathedral Healthcare System today.

As a member of the infectious diseases section of the hospital, I am involved in the diagnosis and treatment of AIDS

patients, and in a variety of research projects aimed at studying the transmission and course of the HIV disease. In my eight years at the hospital as a resident, fellow, and attending physician, I have seen the number of AIDS cases increase dramatically, so that now virtually 75% to 80% of my time is spent on the disease.

In an era filled with sophisticated scientific knowledge and technology, it is an unsettling experience for me as a physician, and for those of us involved in medicine, to face new microorganisms without immediate help from either drugs or vaccines.

But the crisis created by AIDS is not solely a medical one. It is a social, economic, moral, and spiritual crisis as well.

While I am involved in the clinical aspects of AIDS, there are broad policy issues which have an overriding effect on the work I do, and on the lives of the patients I see. While doctors such as myself deal with the everyday reality of AIDS, it is people such as yourselves -- government officials and health regulators -- who, in the end, have much more to say about the future of this disease and about the quality of life for thousands of AIDS victims, their families, and their friends.

More than 50,000 individuals have already been diagnosed with AIDS in the country. By 1991, it is estimated, there will be 20,000 cases in New Jersey alone, which presently ranks fourth in the nation in diagnosed AIDS cases. And for every diagnosed case of AIDS, it is estimated there are 50 other individuals infected with the virus. The effects of this disease, therefore, are truly staggering.

I am here today to ask you to consider several broad areas of concern that need your immediate attention and action, if we are truly to overcome this epidemic:

First is the need for an overall, organized, statewide approach to AIDS. Currently, many different organizations and public and private agencies are involved in some way with AIDS. We need one entity, organization, or person to direct and coordinate the efforts of everyone who is involved in battling this disease. Such broad oversight would eliminate duplication, and would help target funds and resources to those areas in greatest need, and those areas holding out the greatest promise of relief.

The second major area is financial. Hospitals, particularly inner city hospitals such as St. Michael's Medical Center in Newark, are currently bearing the greatest burden in terms of the costs associated with treating AIDS patients. These are invariably the sickest, most debilitated patients we see. They consume an enormous amount of hospital resources, in terms of both personnel and supplies. Their care is extremely costly. Currently, the costs of AIDS cases are not adequately reimbursed through the DRG system. The New Jersey Department of Health has granted special adjustments to help cover the high costs of these patients in 1988, and is in the process of creating new DRGs specifically for AIDS cases for use in 1989 and beyond. However, these adjustments are not adequate to address the high costs of drugs, the severity of illness of AIDS patients, or their high lengths of stay. Additionally, as the technology and treatment patterns associated with caring for AIDS patients change and costs increase, no provision is built into the reimbursement system to address these increases.

Also important is the need for alternative methods of caring for these patients -- nursing homes, hospices, special housing, clinics, home care, and so forth. Too many AIDS patients remain in hospitals occupying acute care beds, when they no longer require acute care, but they are abandoned by family and friends. They have no place to go. They are being turned out of their homes and away from nursing homes, and that

is simply unacceptable. You need to support, promote, and encourage the development of all of these different kinds of alternative care, so that AIDS victims can receive appropriate care in a convenient and cost-effective setting.

St. Michael's Medical Center, along with four other hospitals in Newark, has already taken the lead in this direction by forming a consortium to open a non-acute care facility for AIDS patients, providing a level of treatment similar to that of a nursing home. I urge you to support this initiative as an important step in providing alternative care.

I would also urge you to consider the thousands of individuals who themselves are not AIDS victims, but as children, husbands, wives, parents, and friends of AIDS victims, are also devastated by this disease. It is believed that for every individual with AIDS, there are at least seven family members and friends affected by the disease as well. These individuals need help in caring for their family, in terms of housing, home care, counseling, transportation, and financial support.

For those people particularly, and for all others, education and prevention are essential in stopping, or at least slowing, the progress of the disease.

We as a society are called to respond to this terrible epidemic of AIDS. The issues posed by this epidemic will confront, confound, and challenge virtually every aspect of health care for years to come. AIDS has caused thousands of deaths, generated fear and hostility, yet evoked compassion, love, and generosity in ways seldom experienced in our lifetime.

As a society, we must respond to AIDS with compassion and with justice, and with a very strong commitment to ameliorate the suffering associated with this illness.

ASSEMBLYMAN COLBURN: Thank you. Any questions?

ASSEMBLYMAN OTLOWSKI: Doctor, just one question, if I may.

ASSEMBLYMAN COLBURN: Mr. Otlowski?

DR. PEREZ: Why isn't it possible for the State, through its Health Department, to lease a nursing home for this purpose exclusively?

DR. PEREZ: I don't know the answer to that.

ASSEMBLYMAN OTLOWSKI: Would that work?

DR. PEREZ: Well, nursing homes are part of the solution to the problem we face in the acute care hospital.

ASSEMBLYMAN OTLOWSKI: You were just talking about how important nursing homes are.

DR. PEREZ: Yes, they are important.

ASSEMBLYMAN OTLOWSKI: So, I'm asking you if it would be practical to have a program whereby the State would exclusively lease a nursing home for the exclusive purpose of taking care of AIDS patients?

DR. PEREZ: Certainly it would be helpful. I can't speak on the practicality of it, because I don't know the finances that would be involved, or the hiring of the people to work in a nursing home. But I think that is something that has to be addressed from some source, to provide help for the placement of patients who, right now, do not require acute care in a hospital, but have no place to go after that is finished.

ASSEMBLYMAN DEVERIN: Have you opened that facility in Newark that you mentioned?

DR. PEREZ: It is not open yet. It is in the process of being set up.

ASSEMBLYMAN OTLOWSKI: A nursing home?

DR. PEREZ: It is sort of a nursing home. It is a step-down unit, if you will, one where patients who are perhaps a little bit sicker than the normal nursing home would care for, and yet not sick enough to require acute care beds in the hospital setting.

ASSEMBLYMAN OTLOWSKI: I think it is something that should be taken a look at.

DR. PEREZ: That is one of the main reasons I am testifying on behalf of the Cathedral Healthcare System. We are hoping that something will finally come down the pike that will help in that regard. It has been talked about. There have been attempts made to set homes up. As you know, when attempts are made and progress finally comes around, it always seems to lag behind what is really needed at that moment. That is the situation we are facing now.

ASSEMBLYMAN DEVERIN: What is Cathedral Healthcare?

DR. PEREZ: Cathedral Healthcare is run by the archdiocese, and basically encompasses St. Michael's Hospital in Newark, St. James Hospital in Newark, and St. Mary's Hospital in Orange.

ASSEMBLYMAN COLBURN: Doctor, first of all, I was going to ask Suzanne Ulivi to make copies of your testimony.

DR. PEREZ: You have copies, which were given to Mr. Price earlier.

ASSEMBLYMAN COLBURN: Oh, okay, then we have it. Thank you.

The other thing is: Does the Health Department wish to make any response to the idea of the nursing home, which I am sure you thought of?

COMMISSIONER COYE: (speaking from audience) Yes. What we have been doing, and it has been fairly successful so far, is, since the payment for the care of the patients would be reimbursed by Medicaid, and they have private insurance in most cases, Medicaid, through the Department of Human Services, has decided a rate of reimbursement which is adequate for the special kind of care that AIDS patients need. So we have accepted C of N applications and processed them, and have given approval for two nursing homes to take AIDS patients in large numbers. One of them is established already and one is in the northern part of the State. The one has been taking patients for about nine months now, and is doing a very good job. The

other one in Jersey City, we hope will be opened sometime in the next six months or so.

So, we are slowly cutting away at the need. We are learning a great deal about this, and the types of services that are needed are changing. The third facility will probably be the Newark one that Dr. Perez was just describing. They would negotiate with Medicaid on a reimbursement rate for that, I assume. I am not sure if that is how it is going to be approached, but I would assume that that would be part of it.

I don't think we need to open one ourselves, because there seem to be people willing to provide the services, given the current reimbursement system.

ASSEMBLYMAN OTLOWSKI: I'm sure that Archbishop McCarrick will be in touch with you. (laughter)

ASSEMBLYMAN DEVERIN: He is very persuasive.

ASSEMBLYMAN COLBURN: Thank you. Dr. David Gocke? Did I say that right?

**D A V I D J. G O C K E, M.D.:** You said it perfectly.

ASSEMBLYMAN COLBURN: Oh, I can't believe it. Dr. Gocke is Chief, Division of Allergy, Immunology & Infectious Diseases, Robert Wood Johnson Medical School.

DR. GOCKE: Thank you, Mr. Chairman and Committee. I, too, would like to thank you for the opportunity to appear. I am very pleased and impressed with the evidence of understanding and interest that I have seen already displayed here on the part of the Committee.

ASSEMBLYMAN COLBURN: We have a super Committee. I didn't say that in my introduction, but all of these people are experienced, and they are all interested. They are willing to learn. They are just super individuals.

DR. GOCKE: Right. As you said, I am Dr. David Gocke, Chief of the Division of Infectious Diseases at Robert Wood Johnson Medical School which, as you know, is a unit of the University of Medicine and Dentistry of New Jersey. I am also

the principal investigator on the AIDS Clinical Trials Unit at Robert Wood Johnson Medical School, which is a NIH-funded center designed to develop and evaluate new therapy for AIDS inpatients. I am also the Director of the Alternate Test Site and Counseling Service, sponsored by the State and located in New Brunswick.

I would like to try to be very brief, in view of the time, and just quickly make the following four points: One, it is going to get worse. I know we have all heard a lot about AIDS. We wish it would go away, but I want to say that the numbers are true; the projections are accurate. You heard the Commissioner say that we expect better than a twofold increase in the number of cases two years from now. The health care system is, indeed -- from the point of view of one taking care of AIDS patients and working in the trenches -- near collapse. It is not an exaggeration to say that people are beginning to die on the streets. Many mornings when I walk into the hospital, I will find someone sitting on a bench sick; doesn't have the money to make a phone call; doesn't have a telephone to make a phone call to make an appointment; not sick enough to be hospitalized, but with nowhere to go, and with no one to care for him, and needing help. Obviously, it is going to take more of everything -- more money, more volunteer effort, more time and attention from all of us.

Secondly, I think there is some good news and some reason to be encouraged. First of all, as a professional, I would like to take my hat off to the professionals in the Department of Health. I think Dr. Coye and her staff are pros. They know what they are doing. They are working hard. They have done a good job in coping with this enormous and rapidly evolving epidemic with the limited resources that are available. So I think that is a plus. I think that our State Department of Health is one of the best in the country, and we should support them.

I think research, as you pointed out, Mr. Chairman, in your introductory remarks, has made enormous and remarkable advances about the knowledge of the basic virology of this disease, and I am sure this is going to pay off eventually in terms of a solution to the problem. There is a lot of work going on around the country and around the world, both supported by the Federal government and by pharmaceutical companies, designed to discover new drugs and vaccines. I think that those two will ultimately pay off

It is not, however, going to be a sudden breakthrough, a single step. It is going to be a gradual process, probably; a step-wise process of becoming better and better able to deal with this disease. In an ironic way, this is going to aggravate the stress and strain on the health care system, since we will be keeping patients alive longer and requiring more in the way of medical care.

I think there are two other areas, or points, that I would make. Number one, I would certainly support and recommend legislation to protect individuals with the disease from discrimination. This is real; it is pervasive; I see it. All patients who have this problem are concerned about the threat to their existence and their way of life. I can tell you of many examples of individuals who have lost their jobs; who have been harassed in the workplace; who have been denied insurance; who have been ostracized from their families. So, it is a real thing, and I think that in terms of encouraging the openness that one of the Committee members has suggested before, legislation to protect the individual against discrimination would go a long way in helping us to get the problem out more into the open, so we would be able to reach people at an earlier stage of the disease to improve our efforts at education and prevention.

Lastly, I think there is a tremendous need for additional primary care services of all kinds, but particularly

ambulatory care, out-of-the-hospital type services -- home nursing care, hospices, halfway houses, nursing homes, day-care centers. There is a need for help with transportation and legal services and simply shopping for food and other necessities of life. Many of those tasks, perhaps, would be amenable to volunteer types of efforts, whereas others will require, obviously, significant funding and new legislation.

But, there is much to be done. I certainly would support the idea of a coordinated State plan, or effort, with regional coordinating centers where people who are experts, who know what needs to be done and how to access various services, could coordinate the care of these individuals, as well as coordinate volunteer efforts.

I think I will be brief, Mr. Chairman, and stop at this point.

ASSEMBLYMAN COLBURN: Thanks very much. Mrs. Ogden, questions? (no response) I guess you have addressed the things with which you agree -- things mentioned by previous speakers -- haven't you, pretty much?

DR. GOCKE: I think so, yes.

ASSEMBLYMAN COLBURN: Were there any things you didn't agree with?

DR. GOCKE: Not that I can think of at the moment.

ASSEMBLYMAN COLBURN: Okay. Well, those things evolve. We know what some of them are, but I was just curious.

DR. GOCKE: Right.

ASSEMBLYMAN COLBURN: Thanks a lot. Mr. Mosley? Excuse me, Mr. Mosley, before you start. (brief discussion with aide) Okay, Mr. Mosley.

**D R. S I L A S M O S L E Y, J R.:** Ladies and gentlemen: As you know, my name is Silas Mosley, Jr. I come here today not to argue nor to accuse anybody of anything, but to present the facts that concern the black community.

The black community has five specific concerns here: One of the basic concerns is the lack of what we call "respect" for the leadership, the desires, and what we call the "needs" of the black community in this AIDS crisis. We have heard here today many figures concerning how the virus itself is really rising and causing much death and misery in the community. But what we have not heard here specifically, is that approximately 48% of all the cases in the State of New Jersey is from the black community; 15% comes from the Hispanic community; and almost 1% from other communities. So we can see here from this situation, that 63% to 64% of our cases deal with minorities.

Now, the black organizations, and the black groups, have asked that they be considered a partner in this whole issue. We feel that members of the State Department have not respected this request. The black community is saying: "This problem-- We are in an epidemic. Therefore, we wish to be a partner, and we wish to be treated as a partner." You say you have 6000 cases of AIDS in the State of New Jersey. We're saying here that 48% of those cases are black. Therefore, the entire black community does not have AIDS. You're treating the black community as though everybody in that community has AIDS. We are rejecting the premise. We're saying that the members of our community who have AIDS are just a few. There are concerned citizens in our community who are willing, able, and committed to helping the State Department deal with this issue in our community. We're saying to the State Department: "Look, number one, you're saying you are giving counseling and testing to the people that are necessary. You are giving education to the people that is necessary." The Attorney General has said: "Education is the tool that we must use to stamp out this virus and halt the spread." However, the State Department has ignored this fact that education is an essential part to the minority communities also.

There are cultural differences here. You have to be sensitive to what is going on in the black community and other minority communities, in order to influence their behavior. We pointed out to them, first of all, that people -- for example, the drug addicts-- Most of them do not have, we say, above a high school education. Many of them are dropouts, but we have some college people in there, too. The majority of the literature that you are handing out to these people is way beyond their comprehension. In other words, the literature they are putting out would be suitable to a doctor or to a nurse or to a professional to understand, whereas you have in the black community-- The majority are reading on a fourth-grade level.

Now, when I was with the State Department-- I joined the State Department of Education, and we made the information for young people. We brought all of the literature down to the fourth-grade readability. This went over big in the community. The Education community-- That is the type of document we want. We thought we had an alliance there. But then again, the powers that be in the State Department decided, "No, that type of literature, or that type of booklet, is not sufficient." We are paying out thousands of dollars to people who are supposed to be good at Madison Avenue type advertising. We will put money into that, like, montage, and all of the other advertising agencies. The black people are saying, "Well, you give me this stuff, but I do not understand what it means," and they drop it into the proverbial file six, or the wastebasket. So, it is not working.

We tried to explain to the Health Department, "You have to bring this literature into line with the cultural sensitivity of the people." The black communities are saying, "You are not educating people about the virus or how to protect themselves against becoming infected. Much of the material you

have, which you are presenting to us, is going through what we call "sexual preference," teaching us what type of sexual preference one should have, and we are objecting to that. We feel you are indoctrinating our youth on sexual preference, rather than educating them on precaution and prevention and how to stop that virus from spreading in the community."

Next, the Federal government, in 1987, around about September 9, asked that the State participate in what they call "minority initiatives." They awarded a grant to the minority community strictly for minority organizations, to put up a health education/risk reduction program in the minority community. Prior to that time, there were no black people or organizations involved in the whole education scheme of AIDS -- AIDS had been going on for at least four or five years, here in the State of New Jersey -- with the exception of one black group, Kahaco (phonetic spelling), which is a Haitian group. They gave Kahaco $9000 to take care of close to 50,000 Haitians in North Jersey. That was the only organization in the black community giving out health education.

I was asked to go and monitor this program. I brought it to the attention of the powers that be, that that was an insufficient amount for them to do the job. So it was increased, later on, to, say, forty-some thousand dollars. At that time, when the (indiscernible) came out for minority grants, five black organizations applied for that grant. One of the organizations was called CALM. It wrote a project -- an education project -- here for the City of Trenton in the black community. This CALM proposal went to the State Department, and it went up to the Centers for Disease Control, and it was approved as an educational project. However, CALM, itself, did not have its 501-C, which is a Federal registration number for charity organizations, which everybody here knows. So CALM went to Project Lift and had Ms. Alma Hill, the Executive Director, agree to take over the administration of that grant, but see that AIDS education got out into the community.

I was, later on -- on May 15, 1988 -- asked to go and close out that particular grant, because it had expired on April 30, 1988. When I went to investigate that program, I found, one, that the moneys that had been given for that express purpose, had not been spent on AIDS education. I reported the whole situation, that much of the money had been misappropriated. Forty thousand of it went out. They got a contract -- a $47,000 first installment on the contract. Forty thousand went out, and the Executive Director took a trip to Africa. The moneys that were given -- $40,000 -- went with her. That was to set up a mission in Africa -- a Lift mission in Africa.

Later, I explained to the Department that the funds were being used for all other purposes except AIDS education. There was no AIDS education going on in that black community. This is what I got: "The money is given to a small black organization. Therefore, we do not expect much out of it anyway. So, don't worry about it. She can do what she wants with that money." I objected. I said, "You are crying alarm, alarm. We have here an epidemic in the community, yet you are sitting there telling me that it doesn't matter that the people who we gave the money to are not using it for AIDS education."

They said, "Well, forget about it," and then I got a big smile. As a result, I protested, and I filed a complaint -- a grievance -- with the Department. In retaliation, they used efforts to blackball me from self-government. I talked to the CWA, the union, and other members of the community. A letter was delivered to the Attorney General. A $1 million suit is being filed by the union and the rest of the community against the Department of Health here.

Second, we are asking for a class action on this whole approach they are taking to the minority community, which we feel is deadly. In the counseling situation, we have said, "We have no objection to your bringing in blacks and taking their

blood, as long as you do something positive here. What is happening to our people once you get them into the center and take their blood?" The answer was, "We are giving them testing and counseling." But, if we look at the figures they gave us today, one group said, "We are processing 600 people through our center per month." Now, if you are going to give a person AIDS counseling, it would take a minimum of two hours to even get the patient to the point where he would be ready to listen to you. Therefore, we're saying, "If you have a counselor in that center who is there only eight hours -- from nine to five, and then ready to go home -- it is only humanly possible to give counseling to three people per day." Therefore, that counselor can only counsel 45 people in a month. Now, mathematically, it will tell you that to get 600 people through that center in one month, you would need 11 counselors on that staff.

Now, you know that in that center itself, they do not have more than two or three counselors. The community has been screaming all of this time, "Our people are not getting counseling." What is happening in those centers is, they are being what we call "militarily interrogated." All they are getting is information. They wanted to interrogate and extract information. Once they get the information, they take the blood and say, "Go home." There is no follow-up counseling. The community has written proposals. They have asked for the ear of the Commissioner to get them to her, because we feel she is a fair lady, but this never gets up to her.

We have, in the community, a follow-up counseling situation, which means that we have patients coming back into the community because they have no place else to go. They are going to our ministers; they are going to our social groups. They are saying to us, "Look, I've got this information that I have AIDS. What can I do?" We do not have the resources in our community to, say, do what we want to do to help those

people to readjust their lives and bring them back into the community.

You have heard here today that the community is ostracizing its patients; throwing them out of their homes. That is not true. The problem is, when you have drug addicts, many of the families have put their young people out because they were abusing the home, robbing from the home, because of their drug habit. Now, when they discover that their child -- daughter or son -- has AIDS, they do not continue to ostracize them; they want to bring them back into the community, and they are asking the Department of Health to help them to do this. But the Department of Health has not done that.

Now we get to the grants. CDC authorized, we say, $700,000 for minority grants. Five people applied. The first grant-- The only person who got the money right away in January 1988, was Ms. Hill of Project Lift. The other people procrastinated. People who got grants, they waited until 30 days -- 45 days -- to give them the money, whereas CDC gave them the money, we say, initially almost six to seven months ago. Yet, this money stays in the coffer, and they procrastinate in giving the grants. Now, one organization applied, and it hasn't gotten its 1987 grant yet. Solar House, which is a very prominent center in Newark, New Jersey, hasn't gotten its last grant yet. We see this type of tactic in almost all cases. There is something close to half a million or $300,000 that has not been appropriated to the minority community.

There are always changes, and the stress they put on the minority community-- We are about to tell the State to take that money and shove it, because at this point we are so frustrated. They tell us, "We have the grant." Many of the organizations have extended their money out, on the promise that the State Department of Health would send them this money. Yet, at the eleventh hour, they get back a sheet that

says there is no money there. For example, they told everybody last month, "You have $10,000. Spend it before December 31." The five organizations -- the only ones that got the grant -- took their own money and went out and spent $10,000. Now, two days later -- this week -- they came back and said, "No, don't spend the $10,000 by December 31. We cannot authorize that."

So, here the people have expended all of that money. They were poor to begin with. These organizations cannot afford it, yet they were told to spend that $10,000 before December 31. Now they are saying that they cannot get that money back; they have to wait.

The last problem we want to cover before we leave here-- In this proposition the community has -- we, the black community, resent the fact that there are elements in the State Department of Health that want the community not to speak for itself, but to have other people speak for them. There is a self-interest group here that wants to be declared the spokesman for the black community. We have contacted people from the Assembly of Churches here. We represent 50,000 churches all over the country, with 40,000 ministers. They have asked now to take a positive role. They have not abdicated their responsibility on the morality of the community and taking care of the black people. They have also asked for a partnership. They have put in a grant with the Federal government at CDC. CDC has approved part of the grant. Yet, they sent into the State Department here a request for the State to join in, in this effort, which will be a national effort. We were told that the State Department has lost that project. They can't find it.

This is the type of information we get. Now, we have here to verify what I have been saying concerning these grants and their failure to be treated equitably and justly, Reverend Betty Carter, Reverend Robert Foster, Mr. Samuel Clark, Ms. Edna Thomas, and Ms. Elsie Pilgrim, who can give you all of the

basic facts concerning this, and the racist attitude we are discovering here, to deny us our right to, we say, help ourselves in the community, and join with the State Department and the Federal government in an effort to do what is necessary to help our people.

ASSEMBLYMAN COLBURN: Could you make available to Mr. Kohler any printed material you have about this? We can duplicate it, and then we can ask that it be gone over.

DR. MOSLEY: Okay.

ASSEMBLYMAN COLBURN: We will give it to each Committee member, and also refer it for some comment and some consultation.

DR. MOSLEY: Yes, I have a full package for you.

ASSEMBLYMAN COLBURN: We have what you have. Does anyone else have any other printed stuff with them, which we could duplicate -- any of the folks you mentioned, plus Mr. Coursey?

DR. MOSLEY: Mr. Coursey is here, yes.

ASSEMBLYMAN COLBURN: If we could have that made available to us, we would like to go over it. I don't think we can hear all of it right now. I think we have gotten the gist of the problem.

DR. MOSLEY: Okay, we will give you a package for each member.

ASSEMBLYMAN COLBURN: I would appreciate that, okay.

DR. MOSLEY: Right, all of the material.

ASSEMBLYMAN COLBURN: John can help you if you need anything duplicated.

DR. MOSLEY: Okay, thank you.

ASSEMBLYMAN COLBURN: Mrs. Ogden, anything? (no response) Thanks a lot.

I was going to ask Mr. Holzberg to come up next, with Oliver Bartlett. Are they still around? (indiscernible response from audience) Do you have some material to make

available to us? (indiscernible response from audience) Who are you?

**S A M U E L C L A R K:** I am Sam Clark.

ASSEMBLYMAN COLBURN: Mr. Clark?

MR. CLARK: Yes.

ASSEMBLYMAN COLBURN: I don't want to get into too many details of specific grievances or legal actions, to be candid with you.

MR. CLARK: I have no legal actions.

ASSEMBLYMAN COLBURN: Okay. Well, come on up. We are trying to get some guidance for the Committee as to how legislation ought to go, not exactly adjudication of specific--

MR. CLARK: I have been here since early this morning.

ASSEMBLYMAN COLBURN: I know; so have we all. I will be here a lot later, too. So, I know; I understand it, and I appreciate it.

MR. CLARK: Okay. My name is Sam Clark. I come here with two hats. One, I am Drug Abuse Coordinator for the Martin Luther King Academy in Vineland, New Jersey; and secondly, I am the President of Cumberland County NAACP.

ASSEMBLYMAN COLBURN: Okay.

MR. CLARK: As the President of the NAACP, I am angry, and as Drug Coordinator, I am amazed.

ASSEMBLYMAN COLBURN: Angry and amazed both, okay.

MR. CLARK: Right. I am amazed, number one, at the fact that-- I am retired; I have been retired for 10 years. I was asked to come out of retirement to run the Martin Luther King Center's drug coordinating activities. As a layman, I was not aware of the situation, until I started digging. What I found out amazes me.

There is $500,000 coming into the County of Vineland.

ASSEMBLYMAN COLBURN: The County of Cumberland?

MR. CLARK: Cumberland County, right.

ASSEMBLYMAN COLBURN: Okay.

MR. CLARK: Initially, it was for alcohol abuse. Now it is alcohol and substance abuse; both at one time. As an example, they have a detox center-- You have to recognize -- well, they took the map down -- that Cumberland County itself-- Vineland is 60 miles square. Cumberland County, you would think, is three times that area. We have a detox center in Bridgeton, 22 miles away from Port Norris; 14 miles away from Vineland. Even in the town of Bridgeton, it's three miles up on the hill, and that is where it is noted. That is where the detox center is. Here, if a kid needs some methadone shots, and he is 22 miles away, or 14 miles away, how is he going to get to it?

They have $500,000, and they are too stingy to pay $5000 to hire a driver for the van they have available, to make one sweep around the county and pick these people up. Their comment was: "If they want it badly enough, they will find a way to get here." The apathy is unbelievable.

Secondly, they turn in numbers, "We treated so many people over a period of time." Yes, we treated John Doe today; we treat Doe John tomorrow. We treated Henry Richie today; we treat Richie Henry tomorrow. Check the recidivism. They go to detox; they go to a 28-day program; they go to the street. They go to detox; they go to a 28-day program; they go to the street. There is absolutely no follow-up down in the black community. You have your traditional type, I would say, counseling, per se, that is not being effective. It is not working in my community, and I think the powers that be have to realize the fact that the traditional, clinical type situation that I have heard about today -- "We are treating so many people--" That is so flowery and so fine, but it is not reaching the streets. I am in the streets; I know what is happening.

You need people in the streets, one-on-one counseling. You need follow-up. You need family counseling.

We have taken the posture that you will have to go into the families and have the families get involved; have the churches get involved in the streets. We have a new thing, what we call, "a one-on-one situation," where we are training people to go into the streets and talk to the people. They are not counselors. You cannot train a counselor in eight weeks. I have to say they are "rappers," if nothing else. They go into the street and they talk to the people. If they need help, then they refer them to a professional.

We have family situations where we talk to the parents. We have the churches involved. Unless you get the churches, unless you get the civic organizations, unless you get the parents involved-- You can get all the trained psychologists using big words down there if you want to, but you are not going to do anything about the problem.

It is a problem that is in the streets. As Mr. Mosley -- or Dr. Mosley -- stated before--

ASSEMBLYMAN COLBURN: Is he a doctor?

MR. CLARK: Yes, he is a doctor.

ASSEMBLYMAN COLBURN: I misstated that.

MR. CLARK: He is a Ph.D.

ASSEMBLYMAN COLBURN: I apologize. Are you, by chance-- Am I miscalling you, too? I do not mean to take away anyone's degrees, believe me.

MR. CLARK: Please don't, because I just graduated from high school by a prayer.

ASSEMBLYMAN COLBURN: I think you have gone much further than that.

MR. CLARK: I have an associate degree; that's all.

ASSEMBLYMAN COLBURN: Oh, okay.

MR. CLARK: But anyway, the problem is, we have to rethink the whole situation. It is no longer just clinical -- "We are going to send social workers in there -- because, number one, the first thing a social worker is going to do, is turn those people off.

ASSEMBLYMAN COLBURN: Don't you think that all of us who are dealing with the people down where the troubles are, are frustrated by the government?

MR. CLARK: I know I am.

ASSEMBLYMAN COLBURN: I am, too. Although I am part of the government, I am also part of the other sector. I think we have to try to figure out how to make things effective.

MR. CLARK: Well, that is what we are trying to do.

ASSEMBLYMAN COLBURN: I know; that's why we're here.

MR. CLARK: Okay. My posture is, I think you have to rethink the thing. Number one, find out where that $500,000 is going, you know. I am all for big salaries. I go along with big salaries, you know, and nice cliques.

ASSEMBLYMAN COLBURN: Up to a point.

MR. CLARK: Up to a point, right. But is it really helping the people it is intended for? I don't want to raise a stink about--

ASSEMBLYMAN COLBURN: Well, I think we want to make sure that we are working into the structures that need to be worked into.

MR. CLARK: Where is the money going? Then, reevaluate the existing programs. The old clinical type situation, I think, has gone down the tube. If you want to really reach these people in the street, and stop recidivism, you are going to have to follow-up, and you are going to have to do it-- The amount of money you can give any group won't help. We have to have trained people. We have to make them rethink -- I mean the community itself -- because it is really affecting them. The churches, and the civic groups, and things like that, is where the problem is. They are the people we are working with, to try to see if we can correct it.

ASSEMBLYMAN COLBURN: I appreciate what you're saying. Thanks a lot. I take that to heart.

I think you had your hand up back there.

T A R R E N C E  C O U R S E Y: Yes, sir. Tarrence Coursey, also from the M. L. King Academy. I am also a member of the Black AIDS Coalition, which is a national organization that deals with AIDS. Again, I have attended many conferences throughout the nation -- well, not many, because I just started. But I would just like to reiterate a few things, to make the point clear.

What has happened is, the King Academy was approved for a grant in May of '88. The actual cash did not come until August of '88, and it was only a partial payment of about $15,000. The total grant really only totaled about $40,000. The problem is, people in other agencies make-- The director makes $40,000. So, you are asking a lot of minority organizations to deal with a problem-- You know, you are asking a whole staff and everybody to buy the paper and the paper clips; to do everything that another organization pays one person to do. See, this is not being realistic. I can speak to that, because I am the guy who is out there on the front line. I am the one who gets the call at 10 o'clock at night, or who goes and talks to a 15-year-old girl who has been tested HIV positive, and has to tell her parents, "Your daughter is HIV positive," or has to tell the 15-year-old boys in that community, you know, "This is a serious problem we are confronted with." I am the person who-- You know how you divide a dollar up, and you give out $100, and by the time it gets to me it is only $2.

ASSEMBLYMAN COLBURN: Or one.

MR. COURSEY: Or one. I'm that guy. Really, what we're saying, sir, is, we have mobilized the black churches in our area, and we intend to do that throughout the southern part of this State. In Atlantic County -- again to reiterate what Mr. Clark is talking about, and what Dr. Mosley is talking about -- we just did a national program with NITA (phonetic spelling), where they tested 300 people, and maybe 150 of those

people tested positive. Now, what happened after they tested positive was-- They are just out there now. They are just hanging in limbo. There is no way to prevent them from infecting anyone else. The majority of those people were black IV drug abusers.

Now, what happens is, most of those men are sexually active. So now you have them being sexually active, and now we are having heterosexual problems, because they gave it to a woman, who probably gave it to someone else. In essence, what we actually have-- We only have 140 reported cases. Our statistics are lying to us, because we are only going by the people who have been diagnosed as having AIDS. If we were to look at the people who tested HIV positive, we would really get the gist of the problem we are dealing with.

Very seldom did I hear anyone here say, you know, that we are looking at the HIV positive numbers. Those are the numbers that we really have to begin to tell the people about. We really have to explain the seriousness of being HIV positive versus having AIDS. It's like, you know, a person will say, "I'm only HIV positive. I don't have AIDS," but that does not mean that they can't give the next person AIDS. It is not being made real clear right now, that once you have the virus, no, you are not sick, but you have the potential for maybe making 24 other people sick, and those 24 for making 24 other people sick.

I would also like to take this time to speak about the pediatric cases in New Jersey. We are second in the nation. Eighty-nine percent of those people -- of the babies being born right now are black. I think we have done a fine job with St. Clare's, that being one of the primary pediatric houses in the State, but I think we've really got to step up that process.

I really haven't heard anyone say what's happening in the prison system in New Jersey. Cumberland County has three prisons, with the promise of another one. We have a high

prison population that is infected with the virus. There are no guidelines for county jails. There is nothing to stop a person from going into a county jail and spreading the virus, even knowing what is happening. When a person is released from a prison that has AIDS, he is just released. There is no networking there. There are no direct support services, or anything of that nature. I am just concerned.

ASSEMBLYMAN COLBURN: You're making points so quickly, that I can't write them down fast enough. Wait a minute. As far as the prisons are concerned, I think I read something in the Medical Society's report that spoke of it, but then there wasn't anything said about the person after he was let out of jail. So, you know, you raised that point.

MR. COURSEY: Right. Sir, I'll tell you, if I were incarcerated for about three years, the first place -- whether I had AIDS or not -- I would go, would be to find some physical contact, regardless of whether that person was going to get the virus. That is how these guys really look at it. I mean, we are living in the real world here, and this is how we have to talk to people in the community.

You know, I can talk and use a lot of fancy terms, and things like that, but it really doesn't work. It's pretty much-- It works a lot easier when we get down and deal with the grass roots of the situation.

ASSEMBLYMAN COLBURN: Speaking in their own language, for example. I understand that.

MR. COURSEY: Right, right. Even in the school systems right now, there is not a coordinated effort. I mean, this school system may be doing something, and the other one is doing something else, and because of the political pressures, this school system isn't going to do anything, you know.

ASSEMBLYMAN COLBURN: Yes. I did see the curriculum that was developed between the State Health Department and the Department of Education. Now, I don't know whether it is all going out equally.

MR. COURSEY: It is an optional thing. You can adopt it, or you can--

ASSEMBLYMAN COLBURN: Well, the local boards, I guess, would have a say.

MR. COURSEY: Right. They can either adopt it or leave it. It is not a mandated type of thing.

ASSEMBLYMAN COLBURN: Okay.

MR. COURSEY: What my concern is, is that the black community is the community that is being most affected by this virus at the present time. It is the IV drug abuse community that is being hit the hardest. We, as the black community, are saying, "We have to go out there and do something about this ourselves. We can't just continue to let this progress like it is going."

My point is, it is going to take money. It is going to take more than $40,000. Take in a year-- I mean, '88 is over. We only had $46,000 at the beginning of the grant to start with. I am into '89, and I am not even sure of what I am getting for '89. Do you know what I mean? I have to do a larger job this year than I did last year, because I am learning more about the problem.

ASSEMBLYMAN COLBURN: You haven't found out about the appropriations, I mean, the projected budget for this year?

MR. COURSEY: Right. I have been--

ASSEMBLYMAN COLBURN: It hasn't been passed yet, for one thing.

MR. COURSEY: Right.

ASSEMBLYMAN COLBURN: Do you think any of that has changed in the budget? Do we know?

UNIDENTIFIED MEMBER OF STAFF: I'm not sure.

ASSEMBLYMAN COLBURN: Does anybody know how the budget stacks up for next year in matters of that sort -- for this coming fiscal year?

UNIDENTIFIED MEMBER OF STAFF: As far as AIDS is concerned?

ASSEMBLYMAN COLBURN: Yes.

**D E P U T Y C O M M. C H R I S T I N E G R A N T:** (speaking from audience) The State budget?

ASSEMBLYMAN COLBURN: Yes.

DEPUTY COMMISSIONER GRANT: The State budget is status quo. My estimate would be approximately a million. With the Federal budget, we of course continue to apply for as much money as we can get.

ASSEMBLYMAN COLBURN: Mary?

MS. MESSENGER: The Federal moneys are up a million in the proposed budget.

ASSEMBLYMAN COLBURN: The Federal moneys are up?

MS. MESSENGER: So, it balanced itself out; the State down and the Feds up.

ASSEMBLYMAN COLBURN: Their's are up, and ours are down, it sounds like. But, you know, you are in almost the same situation as the school boards. They don't know what the State is going to give them, and they are supposed to make up their own budgets by a certain date. I can remember one year when I was a Freeholder, when the schools had to have three budgets in one year, because they were going to get this amount of State money, and that amount, and some other amount. It's really hard, so I can appreciate what you say.

MR. COURSEY: Right. I would just like, as I said, to see a concerted effort. One of the things we plan to do, is to formulate a network, so that the people in Newark who are doing the front line work, who have developed the expertise because they have the hands-on experience of dealing with the numbers, can be duplicated throughout the rest of the State. Again, that is a thing that takes money. When we apply for the money, there is no appropriation because it is not there. These are the kinds of things we need to step up.

So, whatever you can do to help in that effort, we would greatly appreciate.

ASSEMBLYMAN COLBURN: I appreciate what you say. If there is anything you would like to write to us--

MR. COURSEY: I will.

ASSEMBLYMAN COLBURN: --we would be happy to receive it, or if you have something now, we will duplicate it.

MR. COURSEY: What I would like to do is show you gentlemen a play. I would like to invite the whole Legislature to see a play we did on AIDS called, "The Limits of Love." Then you could see that the message we give to our community is somewhat different from the message the white gay community gives to their community. Their message has gotten across because, you know, they are more educated, and they moved rather rapidly. Now it is time for us to step up our process and put a lot more emphasis on this, and get the message across. I mean, prevention-- If we can increase prevention, we won't need to work as hard on a cure. As a matter of fact, they never even talked about a cure at the CDC conference I went to. Their main thrust was on prevention and the people who are already sick. They didn't even want to hear it. Right now, we have a lot of people who are sick, and we've got to do something to help those people. You know, they are still human. Most of them are still getting around. We just have to do something to help them. They are able to help themselves -- they try hard -- but sometimes you just get too sick to move around as much as you would like.

As I said, just remember the children. They need help.

ASSEMBLYMAN COLBURN: Okay. Thanks a lot.

MR. COURSEY: Thank you, sir.

MS. MESSENGER: Mr. Chairman?

ASSEMBLYMAN COLBURN: Yes, Mary?

MS. MESSENGER: May I follow up with the Department? I won't take long.

ASSEMBLYMAN COLBURN: Excuse me. Go ahead.

MS. MESSENGER: What type of coordination is there between Health and Corrections, to ensure that the prison inmates who are released wind up in your surveillance and treatment programs? Is there any coordination going on at all?

DEPUTY COMMISSIONER GRANT: (speaking from audience; no microphone) Yes, a great deal of coordination. We have, through our education unit-- For two years, we did counseling prior to discharge of inmates and training of correctional personnel. Corrections now has individual trainees who do the counseling. Individuals who are released who might be HIV positive are not automatically-- They are encouraged to continue the care and treatment. They are free to choose that treatment. I think the reality is that many of the individuals in the prisons who have AIDS are extremely sick, and they are not discharged that way into the population. (remainder of Deputy Commissioner Grant's statement indiscernible to reporter)

ASSEMBLYMAN COLBURN: I would like to ask Mr. Holzberg to come up. Is Oliver Bartlett with you?

**H A R V E Y H O L Z B E R G:** No. Actually, we have Ed Abramovitz, Vice President of Hospital Management at the New Jersey Hospital Association, and Nan Stager, who is the Director of Planning at the New Jersey Hospital Association. My name is Harvey Holzbert. I am the President of the Robert Wood Johnson University Hospital.

ASSEMBLYMAN COLBURN: Should I call you Doctor, too?

MR. HOLZBERG: No, sir.

ASSEMBLYMAN COLBURN: No. You're not a doctor?

MR. HOLZBERG: I am not a doctor.

ASSEMBLYMAN COLBURN: Okay.

MR. HOLZBERG: I am here today on behalf of the New Jersey Hospital Association. I will give you just a summary. The full text of the New Jersey Hospital Association's position paper has been given to the hearing reporter.

In the decade since AIDS was first identified in New Jersey, hospitals have actually been the primary caregivers for people with this terrible disease. As we heard earlier from Dr. Coye, projections by the New Jersey Department of Health indicate that by 1991, the total number of AIDS cases in New Jersey will well exceed 10,000. Hospitals that are treating only a few cases today can expect to be treating many more in another two years, and hospitals that are already stretching their recources -- and that is most of the inner city hospitals -- to treat numerous AIDS patients may have reached the breaking point by 1991, or even before. In light of this bleak outlook, it is essential that hospitals be able to obtain the resources necessary to meet the needs of people with AIDS.

Because AIDS patients require such extensive and intensive care, hospitals are finding that treating a number of AIDS patients can quickly exhaust available bed supplies, staff time, and clinic space. And, as we heard earlier, it is becoming more and more an outpatient disease, although from the hospitals' perspective, the inpatient care continues. Although New Jersey's hospitals are becoming very efficient at treating AIDS patients, because of a lack of alternative levels of care, many hospitals must hold, as inpatients, those patients who could otherwise be discharged to sub-acute care facilities.

The New Jersey Hospital Association has recommended that hospitals interested in developing alternate levels of care for AIDS patients should receive special designation by the Department of Health, as AIDS Resource Centers. There are currently few incentives for hospitals to provide other than acute care to AIDS patients, but many hospitals would willingly become AIDS Resource Centers if funding and regulatory flexibility were available to simplify the process.

AIDS patients are expensive for hospitals to treat. They require longer-than-average hospitalization, numerous episodes of hospitalization, more hours of nursing care, more

psychosocial care, and more counseling than the average patient. Indirect costs associated with AIDS also add up. Increased costs have been incurred by New Jersey hospitals for worker protection and education, discharge planning, waste disposal, blood bank testing, and various administrative costs. Until July 1988, hospitals received no reimbursement for the increased costs of caring for AIDS patients. In July, the Hospital Rate-Setting Commission approved a $600 add-on to hospitals' reimbursement for AIDS patients. However, some hospitals have experienced average additional costs of as much as $2000 for AIDS patients. In April of this year, the Department of Health is expected to create AIDS-specific DRGs -- an action the New Jersey Hospital Association strongly supports.

There are management questions hospitals must address in caring for AIDS patients. Although every hospital is different by virtue of its mission and the community it serves, the New Jersey Hospital Association has developed certain policies on the treatment of patients with AIDS, AIDS related complex, and human immunodeficiency virus. The Association discourages the use of routine or screening testing of hospital patients for antibodies to the human immunodeficiency virus. Patient testing should be limited in the clinical setting to those cases where it is valuable for clinical management of the patient; for follow-up after an accidental potential exposure to HIV; or for screening donations of blood or other tissue.

Moreover, HIV antibody testing in hospitals should always be preceded by an informed consent, and the test should always be voluntary. Because the New Jersey Hospital Association supports the use of universal precautions by all health care providers, patient testing as a means of protecting health care workers for exposure to HIV is inappropriate. All acute care hospitals should be capable of treating AIDS

patients and, therefore, should not transfer such patients routinely. The Hospital Association is not aware of any hospital in New Jersey transferring AIDS patients inappropriately, and is confident that New Jersey's hospitals are caring, to the best of their ability, for all patients who arrive at their doors.

The New Jersey Hospital Association, on behalf of its member institutions, would like to urge the New Jersey Legislature not to try to resolve the issues related to AIDS on a piecemeal basis. Rather, the issues should be addressed through a comprehensive and rational process employing the input of the many organizations involved in the AIDS crisis. A statewide council or consortium with representatives from interested groups and the authority to recommend government policies has been recommended by the Hospital Association as the best way to confront the problems associated with AIDS.

In this regard, the New Jersey Hospital Association strongly supports the concept of an AIDS Advisory Council, with funding by the State of New Jersey as an appropriate vehicle for addressing AIDS. We are heartened by the inclusion of representation from the Association and the Medical Society of New Jersey on the AIDS Advisory Council, and we urge you to support A-3034.

ASSEMBLYMAN COLBURN: Thank you.

MR. HOLZBERG: New Jersey's hospitals have borne the lion's share of the responsibility for caring for people with AIDS. In the fact of diminishing financial resources, stricter regulatory requirements, and rampant shortages of health care personnel, the hospitals of New Jersey have met the challenges of AIDS courageously and, we believe, compassionately.

ASSEMBLYMAN COLBURN: Thank you. In the absence of anyone else to ask you questions, I am going to ask you one.

MR. HOLZBERG: Sure.

ASSEMBLYMAN COLBURN: I was spoken to by a surgeon from South Jersey, who told me that in the course of operations they puncture their rubber gloves more often than we realize. I did not know that, but apparently it's so. He said that the less training someone has in the field, or the less well-trained a nurse might be, the more likely they are to puncture their gloves. He felt there should be more testing of patients who were felt to be at risk. He mentioned a situation in which I believe he said that without authorization, he took blood from a couple of people he felt were at risk, and sent it to the lab. It came back two positives. When he went to find the patients, he found that they had been discharged. They had given false addresses and, you know, they couldn't find them.

So, I think in a practical sense, there may be something more to be considered about the health care worker, in spite of the routine precautions. The routine precaution end of it strikes me as being a little-- How hard is it? When you apply this to everybody, you might become lax. I think it must slow down hospital personnel on what they have to do. I am on the staff of a couple of hospitals, but as a dermatologist I don't spend a lot of time inside their walls, so I can't attest to that. But I think that whole business of routine precautions kind of loses some of its zip in specific instances of some risk. I just mention that. I think it is something we should talk further about, but just using that precaution idea from the CDC as a panacea may or may not be completely justified.

MR. HOLZBERG: I don't know that there are any panaceas, but I can tell you that our experience is that universal precaution works quite well.

ASSEMBLYMAN COLBURN: Well, it is pretty good for other diseases, too -- hepatitis and--

MR. HOLZBERG: That's right, and there really are so few recorded cases--

ASSEMBLYMAN COLBURN: I know that.

MR. HOLZBERG: --of hospital workers who have, in a job-related way, contracted a disease, that I really-- Because universal precautions are now throughout the State of New Jersey and, I suspect, throughout most of the country, I think that probably has a lot-- That is probably one of the major reasons.

ASSEMBLYMAN COLBURN: It also gives them a better sense of security. I have heard of some people leaving their positions. Now, that was about a year ago. I am not sure if this is still true, but nurses, for example, in Philadelphia-- I was told they left a medical school hospital because they were afraid of all of this. I don't know, maybe that is not a problem any more.

MR. HOLZBERG: I think there have been real advances made. While there is always the possibility that people will become lax from any policy that is instituted hospital-wide, that is not true in the case of universal precautions, because we are very careful to constantly monitor it.

You are quite correct in that it does, I guess, slow down the process to some extent. That is one of the reasons, and actually a relatively small cost, compared to some of the other costs inherent in the care of people with AIDS. On the other hand, there have been allowances made in the reimbursement system for the installation of universal precautions.

I think that works quite well. Part of that, of course, is the training of new employees. I think there is far less puncturing of surgical gloves and other kinds of problems that we used to face. It will, obviously, have a positive impact on many infectious diseases, including hepatitis B, I would suspect, which has been a problem for years, and is, no doubt, a more serious problem for hospital workers, frankly, than AIDS.

ASSEMBLYMAN COLBURN: Yes, I realize that. Thank you very much.

MR. HOLZBERG: Thank you.

ASSEMBLYMAN COLBURN: Mr. Mansfield, are you still with us?

**J O S E P H P. M A N S F I E L D, J R.:** Yes, sir.

ASSEMBLYMAN COLBURN: Please come up and have a seat. I feel that we have already met, to some extent, from having read your correspondence, or part of it, anyhow.

MR. MANSFIELD: Yes, that is correct. Don't panic, this is not-- This is a lot of reference material. (referring to the amount of paperwork he is carrying)

ASSEMBLYMAN COLBURN: No, I think I have read more than you will be saying here. I don't know.

MR. MANSFIELD: I'm sorry the Committee wasn't able to stay.

ASSEMBLYMAN COLBURN: Well, we have people representing them.

MR. MANSFIELD: I trust you have my packet.

ASSEMBLYMAN COLBURN: I had one. I read it the other day. Is that what I was given? (affirmative response from staff member)

MR. MANSFIELD: It would be easier to follow it along, to again refresh your memory.

ASSEMBLYMAN COLBURN: I think I read this whole thing; I did. Okay. I got it a day or two in advance, I think, and I read the whole thing.

MR. MANSFIELD: On January 4, 1988, I wrote to Governor Kean with my view on the medical unreliability of condoms as a prevention to AIDS. I also questioned why taxpayers' money should be used to purchase and distribute condoms, since they can be purchased over the counter at various types of stores. Also, I challenged the legal position of the State in the event of suit due to failure of condoms to

prevent AIDS, and the Department of Health endorsing and pushing them as a prevention.

This letter was forwarded to Commissioner Molly Coye for response. Commissioner Coye's February 10, 1988 letter states, in part: "Educational messages, in order of effectiveness, described the best methods of stopping the transmission of the AIDS virus: celibacy, monogamous sexual relationships between uninfected partners, not sharing contaminated needles." Have you read the Department's literature? The bulk of written material addresses condoms almost exclusively as the means of prevention.

In reading the New Jersey State Department of Health Quarterly Progress Report, August 1 through October 31, 1987, "Health Education/Risk Reduction Cooperative Agreement," you will find the following concerning the educational messages endorsed by the Department in packet 1, page 2, objective 2 -- which is on page 15 of this packet: "Through this cooperative agreement, the New Jersey Department of Health awarded a grant for $45,000 to the New Jersey Lesbian and Gay Coalition, to deliver specific risk reduction information on AIDS and HIV infection to the male gay bisexual community of New Jersey during the 1987-1988 budget period."

A little further down: "the printing of 150,000 items for the use of the continuing 'Frisky, not Risky,' and 'Play Safe' educational campaigns." This is a reference. In packet 2, it goes on further. It states about frisky, not risky, as described in this grant awarded to the Coalition, as Contract No. 86-476-AIDS. On page 2 of the August 1 through October 31, 1986 Progress Report, it reads: "The goal is to induce safe sex practices by conveying the message that safe sex need not be dull sex. The message is reenforced by the packaging. The 'Frisky, not Risky' materials are attractive and entertaining, as well as informative. The materials, which share a common theme, exciting graphics, and an upbeat color scheme, consist

of condom cards, brochures, introduction cards, etc." This is not the same message as Commissioner Coye's letter to me, obviously.

I was then referred by the Commissioner to Terrence O'Connor, of the Department of Health. His March 11 response did not answer, or address all of the questions I asked. My March 28 letter was partially answered on July 1 by Mr. O'Connor. The incremental responses triggered something in my professional background, and my July 12 letter addressed the question of the grantees being nonprofit, and submitting proof to the Department of this status. The response by Mr. O'Connor was: "All grantees are nonprofit."

In fact, the Lesbian and Gay Coalition of New Jersey does not have exempt status from the Internal Revenue Service; has never filed required annual reports with either the Internal Revenue or the State of New Jersey; and has not filed its annual reports with the Secretary of State, by law. The certificate of incorporation for the Lesbian and Gay Coalition states that it is a political, activist, lobbying organization. I read this in the Secretary of State's office: "It is illegal to grant money to a lobbying organization."

All you have to do is read the Department of Health requests for the CDC money for this corporation and its awarding to the State. It is packet 3. Ironically, in August of 1988, their certificate of incorporation was revoked by the State.

I know that packet 3 is huge. I will just refer to two specific--

ASSEMBLYMAN COLBURN: Isn't that part of what I received? I read everything they gave me -- everything that Mike Torpey gave me. That was in the packet that was given to the staff, wasn't it -- a few days ago? I was up here on Monday, and I think that is when I read it.

MR. MANSFIELD: I don't remember. I may have stated it further down, I'm not sure.

ASSEMBLYMAN COLBURN: Okay. I just wanted to be sure, because I think I read-- There is a lot going on in my poor mind, but I think I read all of this.

MR. MANSFIELD: Oh, yes, this is overwhelming.

Well, first of all, to understand packet 3, the Federal assistance form is put out by the State of New Jersey to CDC, as a request for money. CDC has provided me with a copy of everything that was given to the Lesbian and Gay Coalition of New Jersey, Inc., at my request. So what you have is the request by the State for specific moneys, with specific justification.

The third piece-- Well, the next one down is the actual granting of the money by CDC, and the last page shows exactly who they granted it to, by name, and in what amount, to the State of New Jersey.

The State of New Jersey has received -- it was released by CDC -- $43,000 to the Lesbian and Gay Coalition. It was on their cooperative agreement dated April 29, 1988. They were also awarded, as a minority -- the Lesbian and Gay Coalition -- $16,000 as a minority grant. They have no legal status as a minority, so why it was awarded this way, I don't know. CDC has not explained that. Why it was even requested, I don't even know. But here you have $59,000 that was released by CDC to the State of New Jersey, and the Lesbian and Gay Coalition never received a penny of it, for good cause, which will come out further down.

Lift has also been mentioned previously. You will note the same grant on page 414. Lift received-- Or, the State of New Jersey, I should say, received $69,792. Lift never got a penny of it, and they didn't deserve it, so that was correct. But, none of this money has been returned to CDC either. So the State still has it. What they are doing with it, is a very good question.

On AIDS Grant 86-476-AIDS, this is a New Jersey State Department of Health clearance request for a health service grant. The proposed contractor is named Personal Liberty Fund of the Lesbian and Gay Coalition, a separate corporation. You can see at this point, and throughout the entire packet I have -- and more information in my folder here -- that without exception, the State of New Jersey has requested that the Lesbian and Gay Coalition of New Jersey, Inc. receive grants.

Now, this is a lobbying, political activist corporation. In fact, the State of New Jersey received requests for money from the Personal Liberty Fund of the Lesbian and Gay Coalition, Inc., a separate, entirely different entity corporation. Their purpose, in the Secretary of State's office, is that it is the education of, and legal defense fund for the Lesbian and Gay Coalition. They have no right to the money, because CDC did not grant it to them. In fact, the money was given to them. If someone were to go into the State, audit their books, see what check was cut, and in the name of whom, they would see Personal Liberty Fund, because they were also audited, and I have reports. There is no question that that money was requested to one person, was given to another, and the Personal Liberty Fund, in fact, shared their money with another nonprofit organization, which I don't want to go into at this time.

ASSEMBLYMAN COLBURN: Would it be customary for the Federal government to audit the State's use of the moneys that come from the Federal government, would you say?

MR. MANSFIELD: Absolutely.

ASSEMBLYMAN COLBURN: On a routine basis, or do they spot check, or what?

MR. MANSFIELD: No. They come in once in a while, as time and manpower permit. To the best of my knowledge, in talking to the Federal government, they have not come into the State of New Jersey since at least 1984. So, the Federal

government has not audited anything for years. A State audit should be done, too, as a separate issue.

So here we have $59,000 given to the Lesbian and Gay Coalition improperly, and $69,000 not given to Lift, but all of these moneys were received by the State of New Jersey, Department of Health; and not turned over to the grantee, which was not proper, but not returned to the CDC, which is also not quite proper, though -- the reverse. So, we have a slush fund being built up, in reality. I believe Dr. Mosley, and others, alluded to this, but more specifically, this is the mechanism by which it works.

Common sense conclusion on my part, based on the facts: You ask for money from CDC. You receive it in the State. You give it to who you want to give it to. You don't give it to-- I am not saying totally. Selectively, certain people are not getting the money. The gentleman before me was a non-recipient of money. We know clearly that money is going into the Treasury and staying there, and being used for whatever other purpose -- whatever hidden initiative -- the Department of Health, AIDS Division wants to use it for.

Now, you've got the reality that CDC demands and requires reports. You've got to account back to them how the money went. These reports have gone to CDC. The common sense conclusion is, somebody had to falsify the report. If they didn't give the grantee the money, they couldn't report back its usage, and yet there are reports on file in Atlanta. Somebody is illegally reporting back to CDC falsification of usage of money.

Now you have to have a second set of books, because you obviously have to know where you really did give the money, and you do need reports coming back to you, because the State may audit you, and they want to know where the heck the money went. So, if the Federal and the State never talk -- and at this point, they have not -- you can run two sets of books very

effectively. This is a common sense conclusion -- speculation -- but it is based on my professional background. This is how it has to work.

ASSEMBLYMAN COLBURN: I was just consulting with my staff member here as to who such charges should be directed to. You know, we are the Health Committee, and those sound like pretty serious charges to me. I would say that they would invoke the action of some member of State government, perhaps a legislator, and we will take that under advisement.

MR. MANSFIELD: I will cover that toward the end of my recommendations.

ASSEMBLYMAN COLBURN: Okay.

MR. MANSFIELD: As a minimum, I have found that the illegal Lesbian and Gay Coalition of New Jersey, Inc. -- illegal from receiving the funds; not that they are an illegal corporation -- was granted, on Contract No. 86-476-AIDS, $36,000; revision one to that grant, $18,000; Grant No. 87-212-AIDS, $32,800; Grant No. 88-341-NAR -- narcotics grant -- $45,000; and on a, if I have it right, HEER -- HERR report, I found an unknown contract number of $74,676 listed, for a total of $206,476, to which it had no legal right.

ASSEMBLYMAN COLBURN: I am just thinking here, I wonder if your charges just couldn't be put on the record without reading everything in here, because I did read it before.

MR. MANSFIELD: Well, it goes beyond that.

ASSEMBLYMAN COLBURN: I know, but we are not exactly a court of law here.

MR. MANSFIELD: Oh, no, I am going to bring it to your attention because you have responsibility as an oversight--

ASSEMBLYMAN COLBURN: Yes, I know. Where's my lawyer? (laughter) Get Mr. Harkness, will you? (referring to Assembly Majority Staff Deputy Counsel, James Harkness) I'm just not sure. I expect to be here a lot longer, but I'm not sure whether I should listen to all of that. I think I read it.

MR. MANSFIELD: Well, not to--

ASSEMBLYMAN COLBURN: I think we can certainly enter it into the record, and then find the appropriate-- (brief discussion among Chairman and aides) How does the State Auditor strike you as being appropriate?

MR. MANSFIELD: He would be, yes.

ASSEMBLYMAN COLBURN: Well, could we dispense with further details about contract numbers and all that?

MR. MANSFIELD: Yes, sure. Number four was merely a letter -- a copy of a letter -- from January of '88 from the Chief Audit Program, showing that this organization did not comply with the Single Audit Act.

ASSEMBLYMAN COLBURN: Which auditor is that?

MR. MANSFIELD: The State of New Jersey. Robert Cartwright signed it.

ASSEMBLYMAN COLBURN: Is that the person who would be looking into this now?

MR. MANSFIELD: I don't know.

ASSEMBLYMAN COLBURN: Well, I just wonder what office-- Could we see the letter?

MR. MANSFIELD: You should have a copy of it in the packet.

ASSEMBLYMAN COLBURN: I do, but I can't fish it out right at the moment.

UNIDENTIFIED MEMBER OF STAFF: Is Mr. Cartwright your auditor?

ASSEMBLYMAN COLBURN: He's Department of Health, it looks like.

UNIDENTIFIED MEMBER OF STAFF: Yes, Department of Health.

ASSEMBLYMAN COLBURN: We would be sending it to another--

MR. MANSFIELD: Right. Properly, he did tell them they were in violation of the Single Audit Act, which was correct.

ASSEMBLYMAN COLBURN: Okay.

MR. MANSFIELD: These final reports are actually due within 120 days of the grant period. That is something to keep in mind, because if you read the next number, 5, there is a June 24, 1988 letter, signed by Christine Grant, to the New Jersey Lesbian and Gay Coalition, P.O. Box 1431. They don't even have an office, just a P.O. box. She talks about-- She notes that the 1985 report was just received, and the report for '86 and '87 was being extended to June 17, 1988 -- way overdue, needless to say. She refers to an underutilization of $1200, referring to, "the long-awaited consumer manual."

By reading the letter in its entirety, you can see that there is definitely a pleading tone by Ms. Grant, for them to clean up their act--

ASSEMBLYMAN COLBURN: I did read the letter.

MR. MANSFIELD: --so that more money could be given to them on May 1. That was the money referred to in the grant that wasn't given to them, and should not have been given to them. So I don't know why this attorney is condoning and encouraging illegal acts, wanting to give out more money. I think that is a very serious ethical question.

The unexpended $1200 that was referred to here for this resource manual for living with AIDS, has never been produced and, in fact, in packet 7, it actually shows $3000 more was granted, to print something that still to this day has not been printed. Now we've got $4200 that, really, nobody can account for, on the grantee's side of the house. They have had continuous problems with this thing, and it never did get out.

I have given you a copy of Commissioner Coye's letter to me, which clearly states her priorities.

ASSEMBLYMAN COLBURN: Well, is that the one where she said she had referred it to the Attorney General, and couldn't tell you exactly what his advice was, or something?

MR. MANSFIELD: No, that was a different problem entirely. That's later.

ASSEMBLYMAN COLBURN: That was a different one, okay.

MR. MANSFIELD: This was to Terrence O'Connor, who followed up in correspondence with me. This is dated May 10, 1988, where the Governor gave my letter to her to answer. She did, and gave me her educational messages in the priority which I have just read. She said Mr. O'Connor would follow-up with any questions I had.

The real message is found in a quarterly report from February to May of '86: "These cards" -- referring to the condom cards, which I will get to in a second -- "are not meant primarily to educate about AIDS" -- an interesting statement -- "but instead to raise consciousness about the possibility of meeting men and having low risk sex. The cards will have an attachment. They will list low risk sexual behaviors, along with, 'My name is, and I am trying to play more safely. I would like to get together.' That is followed by a checkoff section of low risk activities."

I quote further: "On October 28, during the free period, the presentation" -- this was at a college -- "was a workshop on eroticizing the condom." I have no idea why you need to do that. If you understand the problem, you have to be nuts not to do something about it. Why they have to, you know, con people, and cajole them into protecting their lives, I don't know. A strange message!

From another grant -- and I have provided you with copies -- is an educational message which shows how to use the condom and how to clean needles with bleach. Now I know the needle cleaning was rejected by the Legislature, but it was being planned to be taught. That is the point I am trying to make.

ASSEMBLYMAN COLBURN: It was being what?

MR. MANSFIELD: Being planned to be taught, but it was rejected by the Legislature. All educational messages, except one, have come from Federal funding. I heard, out of another grant -- having to do with this resource guide for living with AIDS -- that the State of New Jersey, Department of Health, will bear directly the cost of publishing 1000 copies. This is coming, obviously, from State funds. This kind of gives you a flavor for the real educational message that the Department of Health is pushing. This is a far cry from Commissioner Coye's letter to me, and her message in there. I would think, personally, that her message to the public is: Tell them what they want to hear, and then we will do as we please.

Number 9, is an actual photocopy of the "frisky, not risky" card, and I have an original at home. On this, under "absolutely, positively safe sex," is listed -- and I am not going to read the whole card -- "mutual masturbation." Now, to me, this does not give you any form of protection, unless you are wearing gloves, or something. If you've got a cut -- and this is how AIDS is transmitted -- you will transmit body fluid from one person to the other. Now, I am not suggesting this as a form of sex; I am just pointing out the defective message that is being put out by the Department.

ASSEMBLYMAN COLBURN: I think the Medical Society's report includes that as a questionably safe idea, or something. They've got a list in their report.

MR. MANSFIELD: Do you mean condoms or masturbation?

ASSEMBLYMAN COLBURN: The mutual masturbation.

MR. MANSFIELD: Not safe?

ASSEMBLYMAN COLBURN: No, not according to this.

MR. MANSFIELD: Oh, I wouldn't agree with it either.

ASSEMBLYMAN COLBURN: So it is not universally-- But that is what they're saying here.

MR. MANSFIELD: This is what is being given out.

ASSEMBLYMAN COLBURN: It's possibly safe, I think.

MR. MANSFIELD: One-hundred and fifty thousand copies of these cards, with condoms attached, were produced. Also in their message, they talk about body rubbing to ejaculation as being positively safe sex. Oral sex with a condom is absolutely, positively safe sex.

I feel the Department is promoting dangerous messages that may result in the transmission of AIDS, and ultimately death.

Of real importance is number 10. This comes from a grant from the Department of Health to the Lesbian and Gay Coalition of New Jersey, Inc. It's printed right on there; it's their form. Under program specifications, it very clearly states: "The following program and administrative specifications are required by the grantee as a condition of this award." In other words, you don't get the money, unless you do as we say, in the following specified items. Number 3: "The Lesbian and Gay Coalition will be responsible for purchasing condoms. The State Department of Health and ACSU will be responsible for reviewing and approving label of content, instructions, and other AIDS information. The State Department of Health and ACSU will be responsible for reviewing the purchasing, printing, packaging, and distribution process." This is their requirement of this Coalition.

So now we have seen absolutely, irrevocably the fact that the Department of Health is pushing the purchase and distribution of condoms. There is no way to refute that. It's real; it is in black and white. That's important later on.

ASSEMBLYMAN COLBURN: Not too much later.

MR. MANSFIELD: No, no. I'm really pushing; I'm anxious, too.

ASSEMBLYMAN COLBURN: I'm not anxious, I am going to stay here all night. I am really thinking of the others. I have office hours tomorrow at 8:30. Don't anybody call.

MR. MANSFIELD: I've got death and destruction tomorrow at 7:30.

Item 11 was merely a Trentonian newspaper article, showing that gloves worn by health workers are prone to leakage. You know, of course, that gloves are thicker than latex condoms, and therefore, if latex gloves leak, latex condoms are certainly going to have a serious potential question about them.

ASSEMBLYMAN COLBURN: That is addressed in the Medical Society thing. I think that is another subject, frankly.

MR. MANSFIELD: Right, but it is a serious subject.

ASSEMBLYMAN COLBURN: I know it's serious, but I mean that it is addressed in other studies.

MR. MANSFIELD: Yes, right. The seriousness is mainly because the Department is pushing this as the means of preventing AIDS. It may not be true. It may be killing people. They are actually becoming a merchant of death, with that attitude.

Over a year ago, the Department of Health purchased approximately 50,000 condoms, and has them stored in North Jersey. They allegedly will, or maybe even presently are, giving them out. These have not been verified as to their serviceability and, of course, if improperly stored, they will be defective. This could be another attempt to kill the clients which they are theoretically trying to save. This leads back to the question of legal liability.

I have given you a copy of my letter to Cary Edwards, and his response to me. What he didn't answer, he could have without any client/attorney privilege being involved. Supposedly, the ACLU has been requested to give an opinion by the Department of Health. Nobody has ever denied that it happened. Nobody has affirmed it, but it is still a question. I asked him: "Do you agree with the ACLU that potential possible liability exists, following my premise that the

Department endorses condoms, and if they fail, somebody will sue the State? What is going to happen, like the IUD? If so, what is the basis for your decision?" I have yet to get an answer. I never will, now that he has resigned.

ASSEMBLYMAN COLBURN: Regarding product liability, and that kind of business, I am just going to ask you to stop on that subject right now, because I just don't know how to respond to you on that now.

MR. MANSFIELD: I know. That's no problem.

ASSEMBLYMAN COLBURN: With respect to what we interpret as being criminal activities with respect to these grants-- It sounds like criminal charges to us, as we have tried -- off the top of our heads -- to evaluate them. We would suggest that the information be forwarded to the Attorney General, the SCI -- the State Commission of Investigation -- we are going to do that -- and the State Auditor. That is what we have to do with that information. That is where it will go -- those three places.

MR. MANSFIELD: I'll just hit one more thing, just to bring you up-to-date, because I don't think the Department would have. I sent a packet, far in excess of what you received, to the Inspector General -- the regional man in New York City -- of the Health and Human Services Federal agency.

ASSEMBLYMAN COLBURN: Okay.

MR. MANSFIELD: He has reviewed this. He has shared it with the Washington office. He made an appointment to see Christine Grant on January 19 and, in fact, did come down. Two weeks prior to his coming down, he sent a letter of things he wanted to see and things he wanted to go over. From what I have been told by the Washington office -- from his superiors -- he did not receive much, if anything. At the January 19 meeting, he gave them two more weeks, which was up a week ago today. I am not sure whether he received anything at all to this date. I haven't had the opportunity to follow-up. But

he, in fact -- and this is no secret any more, so I might as well talk about it-- His representative from the Trenton office -- Mr. Tauner (phonetic spelling), the regional inspector -- had a 10:00 meeting yesterday with the Department of Health to go over certain things. I gave him additional information that I did not have previously, as to exactly what organizations, at least in part, make up this slush fund by the manipulation of funds. As far as I know, that is exactly what the man is going to look for now.

If he comes up with something, he is going to go a lot further. It will become a real, full-blown thing. I can put testimony to the fact, from what I have been told, and from what I have seen, that approximately three-quarters of a million dollars is unaccounted for. This is the tip of the iceberg. We could be talking about millions of dollars, when you have a $38 million budget.

I would recommend that by bringing in the State Auditor, the SIC--

ASSEMBLYMAN COLBURN: The SCI.

MR. MANSFIELD: --the SCI, I'm sorry -- in reality, they should talk to the local man in Trenton also, and maybe coordinate, if the Federal government is willing to work that way, and if they are willing to.

ASSEMBLYMAN COLBURN: I think they will have to determine how they are going to do it.

MR. MANSFIELD: Right, but just to pass it on.

ASSEMBLYMAN COLBURN: Okay. Do you have anything else to recommend?

MR. MANSFIELD: Well, let me just touch on one thing that Mr. Cox did -- it's super serious -- and then I'll give you a quick summary on the recommendations.

ASSEMBLYMAN COLBURN: Okay, because we do have to move along.

MR. MANSFIELD: Yes. There are serious problems with the fact that there is intimidation. It has gone on, and will go on, if we are not very careful. For instance, on January 23, 1989, Mr. Hummel held a 10 a.m. meeting with all AIDS Division employees. He bluntly attempted to intimidate them by threats, to not allow public information to be given out. Every person who was there is a witness to that. His words were subtle, but the statement to those employees that those who did not do as he said would be fired, was very clear.

My information has been obtained through my own resources and attempts. I strongly urge the Committee to make a clear statement to the Department, that reprisals on honest employees, of which there are many -- what I am talking about are just a few people -- will not be tolerated. I would also expect the CWA Union to take the initiative in protecting these employees.

ASSEMBLYMAN COLBURN: I think Mr. Cox questioned that, didn't you?

MR. MANSFIELD: He mentioned it.

MR. COX: Yes, I did.

ASSEMBLYMAN COLBURN: You make the request.

MR. MANSFIELD: And it's real; it's real.

MR. COX: Absolutely.

MR. MANSFIELD: These people need to be protected, because they could become scapegoats. A witch hunt is not beneath the dignity of the people involved.

MR. COX: If I may interject, my offhanded remark about the Department getting more bang for the buck than we are aware of, was alluding to what--

ASSEMBLYMAN COLBURN: Do you mean this money coming back into the--

MR. COX: Indeed, there is a lot of money unaccounted for there.

ASSEMBLYMAN COLBURN: Okay. I think we have heard it now from three people.

MR. MANSFIELD: An incomplete list of the players, as I find it, is: Commissioner Coye, Christine Grant, Robert Hummel, Terrence O'Connor, Steve Saunders, Eileen Bonilla, and Kenneth Black, and there are ways to prove exactly that. No problem.

I recommend -- well, I might be repeating the audit part -- a detailed audit, to include criminal investigation personnel, begin immediately on all AIDS Division grants from 1985 through 1988. All Commissioner office and AIDS Division appointees be immediately evaluated--

ASSEMBLYMAN COLBURN: We have all that, right?

MR. MANSFIELD: No, you don't, sir. I just wrote this last night.

ASSEMBLYMAN COLBURN: Oh, I'm sorry. Well, then, be sure we have it.

MR. MANSFIELD: I updated my opinion.

ASSEMBLYMAN COLBURN: I'm afraid I have not memorized each piece.

MR. MANSFIELD: No problem. I appreciate it. All Commissioner office and AIDS Division appointees be immediately evaluated and assessed for dismissal consideration, and Civil Service accomplices be dealt with in accordance with the Civil Service regs of the State.

Governor Kean's office should immediately order the Department of Health to cooperate with the Federal Inspector General and his auditors. The Committee should send a letter to the AIDS Division staff that intimidation and harassment of employees should cease immediately, and should not be attempted in the future. All Division employees should be encouraged to disclose wrongful acts, and should be granted immunity from either direct or indirect reprisals.

An oversight committee, or a liaison from this Committee is required to ensure compliance with the above requirements, and to ensure that a correct code of conduct exists, since it is obvious that no internal controls exist or have been utilized.

Just a reference: If you have not read these memos, read them. There is one in there from a doctor, which refutes exactly what they want to do, or what currently, as far as I can tell, they are doing.

ASSEMBLYMAN COLBURN: This is not in what you gave us?

MR. MANSFIELD: Yes.

ASSEMBLYMAN COLBURN: Well, I read everything in that packet.

MR. MANSFIELD: Okay. The only thing that wasn't there was a letter from Governor Kean, which I just received. That is the final thing. I will just read it in part:

"In that letter" -- in my letter to him -- "you state that the Department of Health desires to distribute condoms. I do not know where you obtained this information, but as I mentioned to you before in a previous letter, this is incorrect." Well, they have lied to the Governor. I asked the Governor, "Why are you -- the State of New Jersey -- distributing condoms?" and he said, "We're not doing it." Here, I wrote in the summertime, and I have a January 31 letter from him saying that he didn't. He is getting this from the Department of Health. The man is not inventing it himself, so the Department is lying to the Governor: "No, we don't distribute condoms."

Item 10 very clearly shows that they have demanded of the Lesbian and Gay Coalition, "You buy them, and we will oversee the distribution process." No question.

ASSEMBLYMAN COLBURN: Okay, thank you.

MR. MANSFIELD: Thank you for your time. I'm sorry I took so long.

ASSEMBLYMAN COLBURN: Mr. Jacobi, are you still here? (affirmative response from audience) Mr. Jacobi is representing the Department of the Public Advocate.

**J O H N V. J A C O B I:** Thank you, Mr. Chairman. I have prepared testimony, which I will merely summarize.

ASSEMBLYMAN COLBURN: Fine.

MR. JACOBI: I won't read it.

ASSEMBLYMAN COLBURN: And you have copies for us, I see.

MR. JACOBI: I would like to thank the Committee, and you, Mr. Chairman, for having this hearing today.

ASSEMBLYMAN COLBURN: It is long overdue.

MR. JACOBI: Well, it is an educational experience for you--

ASSEMBLYMAN COLBURN: It is.

MR. JACOBI: --and, speaking for myself, for me as well.

The Public Advocate comes into these AIDS issues a little bit differently than a lot of your previous witnesses, because the Public Advocate is not a health care provider; it is not an organization like the Department of Health, which oversees health care providers. Our experience in AIDS issues is largely concerned with discrimination issues and entitlements issues.

I would like to touch on an issue that has come up many times in this hearing, which is the question of confidentiality and discrimination. It has been tossed around quite a bit in this hearing so far, why it is necessary for AIDS to be accorded a degree of confidentiality that other diseases are not accorded. I would like to just sketch out a three-part argument for why it is entitled to heightened protection.

The first is one you mentioned earlier, which is that there is a right of privacy and a right of protection from

unreasonable searches and seizures that exists in both the New Jersey and in the United States Constitutions, and in common law and statute. It is a longstanding and a very deeply cherished right. That right does not end the analysis, though. It is a right with limits, and a right with limits that come up in terms of public health concerns, which other members of this Committee have raised.

The other two factors, other than the constitutional right to privacy and the right to be free from search and seizure, concern the effects of not maintaining confidentiality over this condition. The first concern is that public health would not be served by exposing the AIDS condition of people who would, or should, come to public health facilities for treatment. It is pretty widely agreed by public health scholars who have written in literature, that failure to maintain confidentiality over AIDS and AIDS treatment has a tendency of driving the epidemic underground. People are much less likely to seek out treatment, and cooperate in the notification of people who may be infected, and so on, if they are not guaranteed that their identities will be sheltered.

There is a recent editorial in the "New England Journal of Medicine," entitled "HIV Testing is the Answer -- What's the Question?" which discusses a lot of these concerns. Just a very brief quote from that article-- The article dealt specifically with testing, but I think it deals, by analogy, with the issue of confidentiality as well. The author of that article stated: "There is no cure for HIV infection, and the agony of this situation breeds a desire to do something. Because the HIV test is a good one, the desire to use it is strong. Yet technology should not drive policy. The test should be used only when there are sound, well-articulated reasons for doing so, and a reasonable prospect that testing will do more good than harm. At present, voluntary testing, accompanied by counseling, is the approach most consistent with the information at hand."

I think that piece of the argument can be summarized by recognizing that this is a social disease; a disease which, if it is going to be contained, requires the cooperation of the people who are infected and the people who are at risk. I think it is pretty clear that people who are at risk and people who are infected are much more willing to come forward, to be tested, to get the education that the Department of Health and others are offering, and to take advantage of the voluntary contact notification that the Department of Health and others are offering, if they have some sense that the information they are providing is being kept confidential.

The third part of the argument for confidentiality really turns on the discriminatory effect that people whose HIV status is revealed, suffer. The Public Advocate's various divisions have had complaints and have represented a number of people who have suffered various types of discrimination as a result of having their HIV status either revealed or guessed at. Just a very short set of examples: A man suffering from a very painful illness lay unattended in a hospital emergency department for over 10 hours, when he was recognized by one of the emergency department personnel as someone who had tested positive for AIDS. A woman was fired when it was learned that she had spent her vacation nursing a friend with AIDS. A man was refused needed surgery for months, even by a doctor who had previously operated on him, when he tested positive for the HIV virus.

Many people we have been in contact with have been denied admission to residential health care facilities and boarding homes, when it became known that they were HIV positive. We have also had cases of discrimination in schools, prisons, government offices, courts, ambulance services, and even public transportation. One person who talked to us told us that after he had told a bus driver who he frequently spoke to in his commuting that he was HIV positive, the bus driver began going right by his bus stop.

The result of these three pieces of the argument that there is very serious discrimination involved when someone's HIV status is known, is that people are less likely to be concerned -- or cooperate with public health measures when they are not absolutely convinced of the confidentiality they will be accorded, and the constitutional and common law rights of privacy that people have. All, I think, argue that confidentiality must be maintained.

There are, of course, exceptions to that rule. They are very difficult exceptions. They raise very difficult cases. I think they have to be addressed on a case-by-case basis. I think the presumption has to be that confidentiality of medical records and confidentiality of test results has to be maintained.

I want to just briefly address the question of prisons. It has come up a little bit, but it hasn't really been discussed very extensively. There are two issues related to prisons that I would like to address. The first is the quality of health care that people in prisons are getting. It is the experience of the investigators in the Public Advocate's Office of Inmate Advocacy, that many prisoners, particularly prisoners in some of the county jails, are not being treated, and not being diagnosed for AIDS-related conditions for months after they become absolutely obvious. The prisoners are being left in their cells. They are being kept somewhat in the dark as to the nature of their illness. I have no opinion as to why that is being done, but it certainly is contrary to State and Federal law, and contrary to the mission of jails and prisons generally.

It is interesting to note that some county jails -- and I am not sure about the Department of Corrections -- have treated the Surgeon General's pamphlet on AIDS as contraband, and have refused to deliver it to inmates in county jails.

ASSEMBLYMAN COLBURN: That would be a surprise in today's climate of constitutional jails, but--

MR. JACOBI: A surprise, indeed, Mr. Chairman.

I think the other issue I would like to raise very briefly, is the difficult issue of testing in prisons. It is an issue that raises a lot of very legitimate concerns. It has been mentioned here before. The problem that the Public Advocate sees with the issue of testing in prisons, is as the editorial in the "New England Journal of Medicine" mentioned. It is not clear what would be done with the information. Once the information is obtained, it appears that one of the uses that the information would be put to, is to segregate inmates into two classes: those who have tested positive, and those who have tested negative, in order, it would appear, to avoid the people who have tested negative from becoming contaminated, or infected.

The problem with that is, as you know, the HIV tests that are currently available are imperfect, both for technical reasons and for reasons of errors in human application. The result of that is that both groups -- those who have tested positive and those who have tested negative, who are now segregated from each other -- will have the wrong information. They will believe that everyone in the first group was HIV positive, presenting, it would appear, very serious security problems and a lessened inhibition against high risk activity.

The second group would also have the wrong information, and would believe that what is generally considered as high risk activity is not high risk, because no one in that sub-community is infected. That analysis has led the National Bureau of Prisons to stop their policy of universal testing and segregation of prisoners. They are now undertaking a policy of mainstreaming prisoners and segregating prisoners only who act out in violent ways, and create an actual risk of infection.

So, the argument that the proper way of dealing with the spread of the HIV virus is through voluntary cooperation

and education applies in institutions as well. Of course, people who are incarcerated in prisons and people in other State institutions are less able to protect themselves than others. That creates a heightened duty for corrections officials and for personnel at State institutions.

I think it is important to think, when it is being proposed that mandatory testing and breaches in confidentiality are suggested, that the whole thing be thought through, from both the public health standpoint and an individual rights standpoint. I think that when that analysis is worked through, in the vast majority of cases, the result has to be that voluntary programs are the programs that work the best and that protect people's rights the best. Those are the programs that should be continued.

I would like to just address two treatment and shelter issues that have been touched on a little bit previously. I will tie in with what has been previously said. Our concerns -- the concerns of the clients we represent, and seek to represent -- in the treatment area, fall into two big areas that I would like to mention. One is access to appropriate levels of health care.

Now, the people from the Hospital Association mentioned earlier that hospitals have really borne the brunt of treating people with AIDS, and that is absolutely true. There is a tremendous discontinuity of services in New Jersey after one leaves a hospital and attempts to get health care services elsewhere. The Department of Health-- Commissioner Coye mentioned in her testimony, that they are working to develop alternative levels of care, and they are, and that should be encouraged. They have been working to develop nursing home level of care, sub-acute level of care, in the cities of Newark and Jersey City. The direction we come to it from is through representing homeless people. Homeless people are in a terrible level of care dilemma. They get bounced back and

forth from hospitals, where they get acute care, and sometimes stay past the time that they need the acute care, to homeless shelters or living in the streets, the PATH stations, and so on. It is a terrible situation for someone with a serious illness. It leads to a shortened life. Frankly, it leads to exacerbation of existing medical conditions.

One of the social workers who works at one of the large northern New Jersey hospitals described the problem in this way, in an affidavit he supplied for us in one of our actions before the New Jersey Supreme Court. He said: "Most homeless shelters in New Jersey require their residents to leave the facilities during daytime hours. An AIDS patient is in a weakened condition 24 hours a day, and cannot risk exposure to outdoor elements. Moreover, most shelters are overcrowded due to lack of affordable housing, and AIDS patients are at risk of infection in these facilities due to the presence of opportunities for infection.

"In addition, I know of a number of instances" -- this is the AIDS social worker speaking -- "where AIDS patients have been ostracized, harassed, and even physically beaten, once other residents in the shelters learned that that individual had AIDS." What is needed is a continuum of care; a series of facilities from basic shelters all the way to hospitals, that will allow people to be appropriately housed and able to get the level of care they need, without inappropriately drawing on the resources of hospitals and other extreme acute care facilities.

The other treatment issue I wanted to raise, is the problem of the lack of drug treatment centers. You have heard a lot about that from various avenues today, but the Public Advocate has gotten complaints and suggestions from almost everyone we have spoken to, every community group, everyone who is an advocate for people with AIDS, that what is really needed in New Jersey is ready access to detoxification programs; that

there is a shortage of slots in those programs; and that we are faced with the ironic situation of having people coming in volunteering to go through those programs, both to rid themselves of a drug habit, and to end their association with an activity that puts them at high risk of contracting AIDS. They are being told either that there are no slots open for months, or that there is a charge that cannot be waived. It seems to me it is a situation of, "Pay me now, or pay me later." It is just bad public policy not to bring these people in, get them detoxified, and get them out of a situation where they are at high risk of contracting AIDS, to say nothing of the public good in having them no longer have the drug habit.

The other issues that I really will just mention, are the concerns we have of hospitals being appropriately reimbursed for the AIDS care they provide. It is something that I think the Department of Health has worked very hard on, and I think the Department of Health should be given a great deal of credit for dealing with a very difficult issue. They have taken a lot of heat from all sides on this, and they should be commended for the work they have done in trying to address this issue in a way that allows hospitals to be adequately reimbursed, without creating windfalls of expenditures that could be better spent elsewhere.

The other issue that I had flagged as an additional issue, was the jail issue that I addressed earlier.

Thank you, Mr. Chairman, for the opportunity to address your Committee.

ASSEMBLYMAN COLBURN: Thank you. If anyone who comes up next can limit their remarks to five minutes, that would be a mercy. I don't know if you can, because you have certainly listened long and attentively to everybody else.

I did not understand when Dr. Mosley testified, that the people with him might, individually, wish to testify also. I apologize for not knowing that. We now have with us,

Reverend Foster, who I am told has arrived. He would like to say something. Where are you, Reverend?

**REVEREND ROBERT FOSTER:** I'm right here.

ASSEMBLYMAN COLBURN: Gosh, you look like that other fellow who was up here, don't you -- someone who testified earlier? Please have a seat, and tell us what you think.

REVEREND FOSTER: Mr. Chairman, I prepared a written statement of testimony, which will be shorter than five minutes.

ASSEMBLYMAN COLBURN: That's fine.

REVEREND FOSTER: I am before you as a leader of a church that is committed to serving our community beyond the realm of spiritual activity. We have built an educational addition, and provide special education programs. Our journey with the State Health Department in our efforts to become a community-based AIDS service organization began in the fall of 1987. We have some concerns and questions about our experiences on this path, in our efforts to serve the community where we are based.

Our initial proposal was submitted by the November 1, 1987 deadline. At that time, we were urged to do so, being advised that we would be included in an application for funding for 1988. There were several calls made to State personnel, who wrote us as though we were a funded agency immediately after January 1, 1988.

ASSEMBLYMAN COLBURN: Excuse me. Where are you located?

REVEREND FOSTER: We are located in Red Bank, New Jersey.

ASSEMBLYMAN COLBURN: Oh, okay, thank you.

REVEREND FOSTER: In late May of 1988, we received our first official correspondence from the State Health Department. The letter stated, and I quote, that we were "approved for a continuation grant for eight months, from May 1 through December 31, 1988." My calls and questions were

responded to as though the wording of the letter notification was misunderstood by me. We were gently pressured to hire our entire staff by June 1, 1988, and I was sensible enough to know that people would not work without pay. We hired a project director, a team leader, and a secretary on that date, and attempted to get the project in motion.

As neophytes in our interaction with the State, we found that community resources such as the Hyacinth Foundation and representatives from Discovery House were the only real source of information and help in getting our project off the ground. We hired all of our staff as of September 1, with prayers on our lips that money would be forthcoming. Finally, we received our first check on September 14. We scampered to have our staff trained by consultants and to get the word out about the program. We contacted over 25 civic, educational, and religious organizations during the summer, but could not make firm commitments because of the fiscal uncertainty of our situation. We had our project publicized, and staff were making presentations by October 1. Then our real problems with the State Health Department began.

We submitted, as the State directed us, in October, our proposal for Calendar Year 1989. It was a tremendous burden, in that the project had only been in full operation for a month, and we were required to project for 1989 in that first month. Our coordinator attended mandatory State workshops, and we felt as though we were moving in the right direction.

The first really questionable action came from a visit from Ms. Russo, a technical adviser. Her December visit ended with three major cuts and changes in our project, which caused me to wonder whether or not the State Health Department felt we had learned anything from the concept and application of our project. We were told, first, that our submitted 1989 proposal had to be cut by $40,000, because we were only going to be approved for a 9% increase over the prior year. In doing so,

Ms. Russo advised us that we did not need a hotline, and further that we did not need a support group, since we were only providing information, and finally, we needed no consultants for the ongoing training of our staff.

When our coordinator related these changes, as advised by Ms. Russo, I was enraged. I felt we were being told that what we had assessed as the needs of our community were not received in a positive way by the State. Today is February 9. We were promised in October a special grant of $10,000, which had to be committed and spent before December 31, 1988. As of this date, we have not received that money. We have been required to resubmit a new proposal for 1989, which we were told three weeks ago to do, and which we did last week. In doing so, we were told that we would not receive any 1989 start-up money for another month. We have been informed that our staff is too large, and that when a person leaves, he or she is not to be replaced. As of this date, we have enough money to make net salary payments tomorrow. After that, the project will be broke.

I may be a reactionary, and I may also be suspicious, and I may be a little too concerned and committed about serving people. I wonder why it is that while we are in the midst of trouble, our ideas and concepts have not been respected by those persons in the State who are supposed to help us? I wonder why we have wasted so much time doing one thing, and after 30 days, or 60 days, the State tells us to change everything? I wonder what will be the next drastic change in our project, directed by the State with what seems to be no interest or concern about what we in the trenches feel can lift the conscious level of our community?

I pray that other community-based groups have not had similar experiences and, in doing so, have given up. We have, but we will not. We believe that what is wrong can be corrected by the action of this Committee.

I thank you.

ASSEMBLYMAN COLBURN: Thank you. Wow!

REVEREND FOSTER: I have copies of all of this correspondence.

ASSEMBLYMAN COLBURN: Yes, we need that. Please give it to Suzanne Ulivi.

Reverend, we are going to ask the Health Department to answer your questions to us -- to give us the answers on your behalf. I can't explain any of it.

REVEREND FOSTER: I just needed to share it with you, to let you know that we are working, but they have tied our hands at every turn.

ASSEMBLYMAN COLBURN: Well, it is too bad to see those things in your State, but we experienced them with the Federal government and with our county government. It was just totally frustrating. Of course, they are in Washington, but at least we are a little closer. We will try to do what we can for you.

REVEREND FOSTER: I thank you very much.

ASSEMBLYMAN COLBURN: Thank you. Marc Cherna, are you here? (affirmative response from audience) Do you want to step forward, please? Carol Kurland will be next, and then Bernard Rabinowitz, if they have survived.

**M A R C C H E R N A:** In the interest of time, I cut back on my testimony, to try to keep it within the five minutes.

ASSEMBLYMAN COLBURN: I thank you. Has any of it been covered before -- any of what you would have said?

MR. CHERNA: Some of it. It is in the total written testimony, so-- I know there are a lot of people who still want to testify.

ASSEMBLYMAN COLBURN: Yes, we still have some.

MR. CHERNA: I am testifying on behalf of the Department of Human Services, Division of Youth and Family Services. I would like to commend you for having this hearing.

HIV infection is a critical public health problem, and a social problem. The child welfare agencies have

traditionally worked with vulnerable children, families with a variety of problems, child abuse and neglect or abandonment, drug and alcohol abuse, mental health problems, and the effects of poverty and homelessness. Today, DYFS provides services to 210 children with HIV infection, mostly infants and toddlers. Nearly half of these children were born in families already under our supervision.

DYFS does not get involved with every HIV infected child in the State. Our involvement is not triggered by virtue of a medical diagnosis alone. Of the 210 children with HIV infection, 116 are living at home with a parent or relative; 72 are now in foster care; five are in transitional care homes; and six are in adoptive homes. In the past four years, we have provided services to more than 300 children with HIV infection.

In 1984, we only had general policies and guidelines for contagious diseases, confidentiality, and a mission to protect and support vulnerable children and adults. The catalyst for developing a broad social policy came about when a five-year-old girl with HIV infection was denied admission to school. It was then that the full impact of HIV infection and its social, ethical, legal, and medical ramifications began to emerge. DYFS was involved with this little girl because she was a foster child.

The issues confronting the health care and child welfare systems are inseparable and virtually impossible to address in isolation. Medical, psychological, social, and ethical issues are intertwined. Widespread fear and ignorance about HIV infection could not be tackled without sound medical facts about its transmission. Boarder babies could not leave hospitals without specialized foster homes, trained and willing to care for them. Guidelines for case management of children with HIV infection could not be fully developed without expert medical advice.

New Jersey has been a national leader in providing services to children with HIV infection for two reasons: First, because of the extensive coordination between child welfare and health professionals; and second, because of the network of services that has evolved. The late Dr. Jack Rutledge, former Deputy Commissioner of Health, established the State's first Pediatric AIDS Advisory Committee, and brought together experts and professionals in every field to address the critical issues. Under the leadership of Mary Boland -- who spoke previously -- this group of concerned professionals pooled their talents, expertise, and available resources to identify and deliver needed services. This set the tone for joint planning and policy making, which is continuing today.

Terry and Faye Zealand, original members of the Advisory Committee, wanted to use their expertise in residential services to do something for children with HIV infection. They founded the AIDS Resource Foundation for Children and opened St. Clare's, the nation's first transitional care home for children with HIV infection. Start-up funds came from the Department of Health and operational funding from DYFS and Medicaid.

DYFS has focused on four major areas that represent the most critical needs for children with HIV infection and their families: training and education, medical consultation and support, specialized social services, and administrative policies, procedures, and practices.

I would like to outline the most significant advances we have made:

Training and education initially concentrated on caseworkers and foster parents caring for children with AIDS. DYFS was the first Division to require mandatory training. The statewide training for all DYFS staff is also open to foster and adoptive parents, child care staff, and the general community.

"A Practical Guide to Caring for Children with AIDS" was developed by the DYFS Medical Unit for foster parents and prospective foster parents. The Guide gives straightforward information about transmission, infection control, the course of the disease in children, and coping with the emotional stress from the social stigma attached to AIDS victims.

The DYFS Medical Unit also developed "Policies and Guidelines for Case Management of Children with HIV Infection," with extensive consultation from the medical and legal experts. The policies provide a consistent and balanced approach to casework practice and decisions about screening, testing, and disclosure of information. These policies have been used as a model by many other states.

The DYFS Medical Unit is on call 24 hours a day to provide case consultation to DYFS caseworkers and foster parents. Technical assistance on program development is also provided to community-based organizations.

Transitional homes have opened in Elizabeth and Jersey City. Others are in various stages of development. It is important to note that local communities have been extremely supportive of these efforts and should be commended for their actions.

Contracts were developed with CHAP and other hospitals with expertise in pediatric HIV to provide case consultation and medical support.

With the help of the Foster Parents Association and the Urban League, efforts to recruit, develop, and train specialized foster home providers to care for HIV children have been very successful. Approximately 65 homes have been approved to date.

Contracts with community-based organizations to provide support services, such as homemakers, transportation, and counseling, have enabled many HIV infected families to remain intact.

The nation's first Head Start Program for preschoolers with HIV infection was established in Newark by Babyland Nursery and New Community Corporation. Their funding comes from the United States Department of Health and Human Services and DYFS.

In some cases, we have been able to stabilize the family and link them to community services, and gradually reduce or discontinue our direct involvement. That would not have been possible a few years ago. Boarder babies are now the rare exception in this State, instead of the rule. Thirty-eight children with HIV infection are now in some stage of the adoption process.

However, much more needs to be done now and in the future. While the majority of children with HIV infection are at home with the parent, relative, or foster family, it can be physically and emotionally draining. Respite care is needed to allow families to recharge and keep families intact and prevent disruption.

Hospice care is desperately needed for children and families in advanced stages of the disease. Specialized child care for infants, preschoolers, and school-aged children is needed. Specialized infant stimulation programs are needed to offset the severe developmental delays associated with HIV infection. Increased mental health intervention is needed. As children live longer, AIDS dementia will surface more frequently.

Specialized services for adolescents will be needed. Given the level of drug involvement and sexual activity among teen-agers, more adolescents are likely to be diagnosed with HIV infection.

These are just a few areas of need. However, I am confident that with your continued support, New Jersey can continue to meet the challenge.

Thank you for giving me the opportunity to testify.

ASSEMBLYMAN COLBURN: Thank you. That was pretty fast.

MR. CHERNA: I tried to go through it quickly. You have the full testimony, if you care to read it.

ASSEMBLYMAN COLBURN: I thought you were a tobacco auctioneer. (laughter) Thanks a lot. That was well done.

MR. CHERNA: Do you have any questions?

ASSEMBLYMAN COLBURN: You mentioned hospices. I think we were going to ask about hospices of Carol Kurland, if she has withstood this.

MR. CHERNA: Yes, she is still here.

ASSEMBLYMAN COLBURN: Come on up, Carol.

MS. MESSENGER: Mr. Chairman, a quick question?

ASSEMBLYMAN COLBURN: Oh, sure, excuse me. Go ahead, Mary.

MS. MESSENGER: If a child is under DYFS' supervision, and the parents are known IV drug users, is the child tested regularly automatically, or is that something foster parents would have to request?

MR. CHERNA: We would usually test the child. If the child were going into foster care, we would test the child because he or she would be high risk.

MS. MESSENGER: Regularly, or just at the time of placement?

MR. CHERNA: With medical consultation, the child would be tested initially. It depends on the age of the child. If a child is an infant or under two years old, he or she would probably be retested because of the transfer and we need the current status. If the child is over two years old and tests negative, then he or she would probably not be tested again, unless medically indicated.

MS. MESSENGER: Medicaid picks up the costs?

MR. CHERNA: Yes. Carol can speak to Medicaid picking up the costs.

ASSEMBLYMAN COLBURN: The costs of any testing that is medically requested. I think when they follow these patients, they have to check their lymphocytes periodically, their white blood count, to see how they are doing, so that would probably fit in with what you asked.

MR. CHERNA: Yes. If a child is symptomatic, then the child would more likely be tested, even at an older age. If a child is healthy and has tested negative and is over the age of two, then it would not be medically indicated to test again.

ASSEMBLYMAN COLBURN: Thank you. Good evening, Carol.

**C A R O L H. K U R L A N D:** Good evening. That's right, Dr. Colburn.

ASSEMBLYMAN COLBURN: We're still here, right.

MS. KURLAND: I am representing the Department of Human Services, Division of Medical Assistance and Health Services, known by its more familiar name, Medicaid.

ASSEMBLYMAN COLBURN: Medicaid, right?

MS. KURLAND: Right. I administer a rather unique home care program for Medicaid called the AIDS Community Care Alternatives Program. I passed out little packets. They do not contain my testimony, but give you a fact sheet and a brochure and some other data on the Program.

ASSEMBLYMAN COLBURN: Okay.

MS. KURLAND: I just want to say that although there has been a lot of focus placed upon the Department of Health, speaking for Medicaid, in Fiscal Year 1987, we expended $14 million on persons with AIDS and ARC, and we are projecting a $20 million budget in '89. So, we are a large funder of services for persons with an ARC.

Recognizing the need for an innovative, cost-effective, statewide home care service delivery system for persons with AIDS or ARC in New Jersey, in late '86 our Department submitted a proposal to HCFA -- the Health Care Financing Administration -- requesting approval of a three-year

Medicaid waiver. I will give you the technicality: Under section 2176 of OBRA -- the Omnibus Budget Reconciliation Act of 1981 -- this proposal was initiated by our Department, but received a lot of cooperation from the Department of Health, the home care industry, and advocacy groups.

The purpose of the Medicaid waiver, as it has become known, is to help eligible people to remain in the community, or to be returned to the community, rather than being cared for in a long-term care facility or hospital setting. We went through various waivers of Federal Title XIX Medicaid regulations, and we were approved with an effective date of March 1, 1987, making New Jersey the first State in the nation to have a Medicaid waiver.

Since then, several states have followed. We have consulted with, I would say, about 75 various state and governmental bodies and private citizens to give them information about the Program. It has become very well-known across the country.

The waiver permits our State to serve, at home, individuals who are both current Medicaid community eligibles and, by using institutional standards, also who would, without the waiver, enter a nursing home or a hospital. So, we serve those people. We waive the eligibility standards, and allow them to be served at home in the community.

It also allows us to provide an array of Medicaid services that are nontraditional; those that are not covered under our regular program; that are geared to the needs of this population. We used the New Jersey Department of Health data submitted to CDC to determine how many we would serve, and we arrived at a figure of 350 the first year; 600 the second year; and 1000 the third year. As with any new program, start-up was slow. However, we have served, since the Program began, 665 persons in this Program. Unfortunately, about 320 of those persons have terminated on the Program, mostly due to death.

ASSEMBLYMAN COLBURN: Excuse me. Are they scattered throughout the State?

MS. KURLAND: Yes. This is a statewide Program. We allocate what we call "slots" -- appropriate in this State -- to various counties in New Jersey, depending upon the known numbers of persons with AIDS. The length of time in the Program has ranged from one to 20 months. We have one person who has been on the Program for 20 months -- who has lived that long. To be eligible for the Program, people have to be sick. These are people who need our Medicaid institutional level of care. In other words, they would be eligible to enter a nursing home or a hospital. They also have to be diagnosed as having AIDS or ARC, or if a child under the age of two, have HIV positive. Fifty-six percent of the enrollees are current Medicaid community eligibles, and they go on the Program to get additional services, whereas the rest were people who would never have gotten on Medicaid in the community without this waiver.

We waive spousal and parental income and resources to allow people on. You look at the person's own income and known resources, and that has been a real benefit to children coming on the Program.

Individuals under the age of 65 -- this is a Federal requirement -- must also be determined disabled, either by the Social Security Administration or by the Division of Public Welfare. Each person on the Program is asked to share in the cost of the Program. However, because of the minimal income of most of these people, we have had very little cost share.

Services on the Program are provided within cost limitations of a hospital cap, because without this Program most would be in a hospital. We have allowed a generous service cap of $12,960 a month, although our history -- our experience has been that people are spending only $2200 a month in the Program. But for those very sick who need extensive

care, we provide up to 16 hours a day of private duty nursing, and the ability to use the higher cap is there.

Services include all those that are covered under Medicaid, except nursing home care, which is disallowed under the Federal regulations. Additionally, we allow special services of case management, private duty nursing -- as I said, up to 16 hours a day -- unlimited hourly personal care services, narcotic and drug treatments at home, intensive foster care, and we have a contract with the Division of Youth and Family Services -- our sister agency -- where we help to pay part of the costs for foster care parents under the waiver. We pay for a specialized group of foster care homes such as St. Clare's. We pay a portion of the cost of that care -- a per diem cost. We pay for a specialized medical day-care center -- Straight and Narrow -- in Paterson. We give them a special rate over and above our normal rate. We helped them to establish that program.

Case management is a pivotal service under this Program. People receive-- Each person is assigned a different case manager who is either a public health nurse or a master's prepared social worker. All the adult case management sites are located in home health agencies, and the children are managed through the special Child Health Service Units of the Health Department. So, we have worked a cooperative arrangement with them. Case managers work with the client, with the family, with the provider, and help to formulate a service plan, and then assist in implementing the plan and monitoring it. And of course, we always operate this within a climate of cost-effectiveness, and call it insurance.

As I said before, New Jersey is the first State in the country to have a medical day-care program specialized for persons with AIDS and ARC. We are hoping to have the second one very soon on this great interest in this particular service area, where people come together during the day, receive all

their health care services, nutritional services, and are able to share socially with people of their own age and interests.

We have learned from our case managers that the people in this Program are normally sicker than people who have been served in a nursing home, supporting our contention that people do prefer to remain home, when at all possible. The individuals mirror the risk groups of the State's population reported to CDC by our Department of Health. You will see a little colored chart in the handout -- well, halfway through -- that demonstrates the comparison of the risk groups. They are very similar to the Health Department's risk groups in this Program.

We serve a sizable number of women under the Program. Twenty-six percent are female; 74% males, which is dramatically larger than the national population. The age groups of the clients in the Progam are diverse. The majority, of course, fall within the 21 to 50 age group; 440 to 655 are in this group. But we have served children under five and adults over 65, so it is not strictly related to that population. We have 60 children under the age of 13.

As might be expected, the northern urban counties have the preponderance of AIDS cases. Our largest, of course, is Essex County. In our Program, we serve 248 people; 83 in Hudson, 43 in Passaic, 52 in Union. Monmouth is the fifth next, with 37. Then, there are a number in the 20s, so it is spread all over the State. Every county has one.

ASSEMBLYMAN COLBURN: Has there been at least one in each county?

MS. KURLAND: Yes.

ASSEMBLYMAN COLBURN: Every county has at least one?

MS. KURLAND: Yes.

ASSEMBLYMAN COLBURN: Okay.

MS. KURLAND: A large number of our recipients have returned home to live with their parents, which is a different

phenomenon. Many times, they have to go home to a senior development, and they are not too well accepted, so they have a very difficult time. Thirty-nine percent of our people have gone home to live with parents. Although the large majority of them are between the ages of 21 and 50, they have been independent most of their lives, and the additional psychological trauma of going home to live with parents is another factor.

Briefly about the costs. The last sheet in the handout shows you what we did during Calendar Year 1988. Over the period, we spent $8.4 million on this Program, serving an average monthly population of 311 people, with a monthly per capita of $2262.

Some of the problems we have encountered in our two years of operation of this Program include-- There is a scarcity of needed home care services in the State, which I think you have heard about before. It is not only in the area of serving people who have AIDS and ARC, but the elderly population and serving children. So, there is a terrible shortage of nurses and home health aides, both of whom are essential to a home care program. Without our case managers advocating for these services, it is doubtful that many of them would have received them.

Additionally, transportation is scarce. It is very difficult for people to travel to homes in some of the areas where these people live.

Homelessness is an additional problem. If you don't have a home, you can't give a home care service program. So, this has been a real problem with Medicaid providing services to needy people. With a home located in an unsafe or dangerous area, providers are reluctant to serve persons with AIDS. Escort services are utilized heavily in some of our North Jersey urban centers.

Many persons with AIDS do not have a family or community support network, which is so essential to an effective home care program.

Drug abuse: A great number of our recipients, as I explained, have been, or are drug users. This brings new problems in home care. Addicts continue on drugs, despite the severity of their illness. In fact, sometimes they increase the usage. The drug abuse interferes with the plan of care. Drug dealing continues in the home, causing fear among family members and providers. Providers, at times, refuse to continue services as a result. So, all of this impacts upon the provision of a good home service program.

Children, also, have been a major factor. Finding specialized foster care homes and intensive foster care has been a focus -- as Marc Cherna explained to you -- of our State child welfare agency. We have tried to incorporate the costs of some of these services into the waiver, so that Medicaid dollars could be used to relieve the "boarder baby" syndrome.

With all this, we feel the AIDS waiver has been very valuable to New Jersey residents for several reasons: It provides an opportunity for individuals to choose home care, rather than being institutionalized. That is so important. It provides the State with the ability to work with persons with AIDS, ARC, or HIV within a uniform statewide service delivery system, where we can address problems and try to control costs. It provides the State the capability of using State and Federal Medicaid dollars to pay for some services that are needed, which are beyond the scope of our regular Medicaid Program, but are more cost-effective and within distinct cost limits. It encourages a standardized quality-assured system, carefully monitored, using case management as a function to assist them in getting people needed services.

And it encourages the networking of many levels in departments of government, which has been a marvelous eyeopener

for us. We have worked very closely with a number of other departments, particularly with the Department of Health, and together we have advocated for, and helped recipients of this Program. Finally, it focuses attention on an illness which requires unique and specialized attention, if we are going to reverse its rapid spread and accompanying escalating public costs.

I just want to say that we received word yesterday -- and I was told to tell you this -- that we received a national award for this Program from the American Public Welfare Association, what is called their "Successful Project Initiative Award." We were one of 160 agencies that applied for this, so we are very proud of this distinction.

ASSEMBLYMAN COLBURN: How about that? Very good.

In a sense, I guess this would take the place of the hospice for the individual.

MS. KURLAND: No. Hospice could be a service under this Program. We have been approached by hospice organizations to incorporate it, but because of budgetary constraints, we have not been able to. However, we would like to do that when the budget permits.

ASSEMBLYMAN COLBURN: You would attract some Federal money if you did that.

MS. KURLAND: Oh, yes. With all of our services, there is a 50/50--

ASSEMBLYMAN COLBURN: So, we need our State match for that, right?

MS. KURLAND: It has to be a 50/50 match, yes.

ASSEMBLYMAN COLBURN: I have run into that in some other areas -- that problem.

MS. KURLAND: Right.

ASSEMBLYMAN COLBURN: What do you think the State would have to put up?

MS. KURLAND: Gee, we did an analysis. It was very minimal, because we don't anticipate too many people in this Program using it. It is for specialized people within a specialized program. We do have the figures in the office, if you would like them.

ASSEMBLYMAN COLBURN: Yes, I think we would appreciate it if you would sent them over to John.

Okay, thank you very much.

MS. KURLAND: Thank you.

ASSEMBLYMAN COLBURN: Mr. Bernard Rabinowitz? (no response) Well, he gave us his packet, which is impressive. Diane Palladino, New Jersey Women and AIDS Network? Are you still surviving this afternoon?

**L O R R A I N E S T A N L E Y, E S Q.:** First of all, Diane Palladino was unable to be here today.

ASSEMBLYMAN COLBURN: Oh, I'm sorry. Okay.

MS. STANLEY: Diane is the Chair of the Legislative Committee, New Jersey Women and AIDS Network. I am Lorraine Stanley, a member of the Legislative and the Steering Committee of the Network. I am fortunate enough to also wear two hats, which is not just to be a member of the New Jersey Women and AIDS Network, but I am also the Senior Staff Counsel for the American Civil Liberties.

ASSEMBLYMAN COLBURN: The ACLU. Where are you located -- your office, for example?

MS. STANLEY: The ACLU office?

ASSEMBLYMAN COLBURN: In Trenton, is it?

MS. STANLEY: Newark -- Washington Place in Newark.

ASSEMBLYMAN COLBURN: Newark, okay.

MS. STANLEY: The New Jersey Women and AIDS Network was formed in May of 1988. Currently, we have over 100 members, which include not just individuals, but a very wide, diverse range of representations by both public and private groups throughout the State.

The goal of the New Jersey Women and AIDS Network is to ensure that the impact of HIV infection on women in New Jersey is understood and is addressed through appropriate legislation, psychosocial and medical services, education, and prevention efforts which are relevant to the situation of women who are at risk. To this end, we would like you to consider the circumstances of a typical woman who is infected with the HIV virus.

Jane Doe is 28 years old. Her partner of five years had been an intravenous drug user, but had been clean for the last seven years. He was diagnosed with AIDS, and died six months ago. Ms. Doe has two children, one six-year-old and one three-month-old. When the baby was born, the doctor suggested that it be tested for the HIV infection. The baby tested positive. Jane Doe has relied on hospital emergency rooms for the primary medical care for herself and her children. She worked in a factory before her partner became ill, but stopped work in order to care for him, and cannot return to work because of the new baby.

She is currently on AFDC. She cannot afford the rent on her apartment, which was affordable when she and her partner were working. She is afraid that she will have to move and cannot find a place which is both close to school for her older child, and is affordable on the allocation she now receives. She has been getting chronic infections and has been treated for them over the last year at the emergency room of a local hospital. She has been feeling sick herself, but ignored her own health because she has too much to preoccupy herself with since her partner became ill. She is now very frightened because of the medical situation of her younger child. Her older child now refuses to go to school, because the other children make fun of him, and say, "He has AIDS."

What services are currently available to Jane Doe to help her to cope with her present situation?

Medical care for herself: She needs to locate a primary care physician who is knowledgeable about the HIV infection. Since her partner was HIV infected, and so is her most recent child, it is probable that she is also infected. Her illnesses are most probably symptoms of HIV infection, which were not so identified by the physicians who treated her at the emergency room. Since she is on Medicaid, locating a primary care physician who can work with her on an ongoing basis is almost impossible. At best, she will have to experience long clinic waits to be seen, with her two children waiting with her. She will probably get sicker in a short period of time.

Medical care for her children: Fortunately, there is the Children's Hospital AIDS Program at the University of Medicine and Dentistry in Newark. Here she can get comprehensive care for her younger child. However, she does not live in Newark. This means finding transportation to the hospital and arranging time around her other child's school hours.

Home health care: She is not yet sick enough to quality for a home health aide and she has no access to homemaker services. She still has to do the usual chores of shopping, cleaning, cooking, and watching after the children herself. Neighbors and friends who would be there for her in other circumstances may not make themselves available now, since HIV infection is the problem. She may not even be able to tell family and friends of the illness because she is afraid of their reaction and their rejection.

Counseling: She can go to a local community mental health center for counseling. However, there has been no State-sponsored initiative to train mental health workers to work with HIV infected women and families. In addition, most community mental health centers are overburdened and have long waiting lines. Jane may not live long enough for her name to come up on the list for services.

Support group for herself: There are currently no support groups for HIV infected women. All support groups in the State welcome women, but most women are not willing to go to groups which include gay men and drug addicts. Most of these groups do not specifically address the needs of HIV infected women, nor do they address the ethical and cultural issues that are part of the lives of women.

What can Jane do to protect the future of her children? As it now stands in New Jersey, she has several options: She can put them in foster care; she can release them for adoption; she can appoint a legal guardian through the courts; or she can appoint a guardian in her will. For most mothers, the first two options -- foster care and adoption -- are not seriously considered. No mother wants to lose her children. Even if she were willing to consider adoption, she would lose contact with here children, because open adoption is not yet sanctioned in this State.

If she were to appoint a legal guardian through the courts, she would have to surrender her children to this guardian, and would risk her right to oversee their welfare while she was still alive. If she chooses to appoint a guardian in her will, there is no guarantee that this request will be implemented after her death, if a grandparent or other relative chooses to contest her will. Additionally, being in her financial situation of being on AFDC, there is very little option for legal services available to her. Legal services, countywide, do not provide the service of writing up wills for people who cannot afford to hire a private attorney. While these choices are limited, where does Jane go to get her legal advice?

Hospitalized care: At some point, Jane will need hospital care for herself. She will have access to only those facilities which accept Medicaid -- facilities which, at this point in time, are overburdened and understaffed. She will

need to have a place for her children while she is in the hospital, and her younger child may also be hospitalized at another facility. The stress caused by this state of affairs will only serve to further depress her immune system, and will exacerbate her illness.

After coping with the lack of adequate medical, housing, psychosocial, and legal services, Jane Doe will probably die seven weeks to seven months after she is diagnosed as having AIDS. These are real statistics: Nationally, women with AIDS live an average of seven months after diagnosis, half of the time men similarly situated or diagnosed. In New Jersey, Dr. Pat Klosser, at the University of Medicine and Dentistry in Newark, sees many of her female patients die within seven weeks of their diagnosis. There is no reason to believe that Jane will beat these odds.

But, what could have been done for Jane if things were different in New Jersey?

She would have had access to a comprehensive HIV center, which specializes in providing services for women. Connecticut, a state with fewer HIV infected women than New Jersey, has established such centers. This center would be one of a regional network of centers especially designed to address the total needs of women with HIV infection. Initially, the center would have provided Jane with information on HIV infection, transmission, and symptoms. She would have been counseled about being tested, and the implications of the results of that test. She would have access to support groups and to ongoing counseling services. She would have been assigned to a case manager who could integrate her medical, psychosocial, and legal needs within a comprehensive care model.

She would have had access to graduated medical care in one facility which would provide services from the beginning of her infection, even during an asymptomatic phase, and which would be coordinated with local intensive in-hospital services.

She would have had access to housing facilities specifically for HIV infected women, where she could live with her children for as long as she could care for them. She would also have day-care and homemaker services provided to ensure her being able to carry on with her life for as long as possible.

She would have had access to legal services so she could make decisions for her children after her death. She could better endure her debilitating illness knowing that she had provided the best security for her children as she was able.

Jane Doe has died and is just one of the 1126 women to have AIDS in New Jersey. This number represents an 88% increase in just one year in New Jersey. The State also has the highest percentage of women with AIDS in the country -- 20%. We ask you not to allow this to continue for other Jane Does who are now HIV infected, and who will become infected. We ask that you make the decision, in your capacity as public servants, to act now on behalf of women.

You convened this hearing so graciously to see what it is people feel the Legislature would be able to do for people with HIV infection, ARC, and AIDS. There are a few suggestions I would like to bring up. I think the first thing the Legislature should do is to make sure it is sensitive and concerned. It should be a model for the general public. It should pass legislation that is an attempt to educate and to bring the fears and the hysteria and the panic within the general public under control.

There are issues which are of critical importance to people who are infected. The first is confidentiality. I won't-- Instead of repeating all of the reasons for confidentiality, I would just like to say that I support the position of the Public Advocate and his reasoning as to why we should have confidentiality.

The other area we need to concentrate on is discrimination in all forms. We are most fortunate to be in the State of New Jersey, where our law against discrimination does define AIDS, or a perception of AIDS, as "handicapped." I'm sure you are all aware that the Federal government has amended the Federal Rehabilitation Act, effective this March, to include AIDS as a handicap under the Federal statutes. Unfortunately, with the disease of AIDS, the problem we have is not the protection -- legal protection of discrimination, but rather the method of ensuring that people are protected. People who are diagnosed with AIDS do not have the time to go through the traditional legal system. They do not have years to wait for their case to come to court and to receive back pay. They're dead.

What we need is that the Division of Civil Rights be encouraged, and perhaps funded, to expand their Dispute Resolution Units, which are specifically designed to handle situations like this; that is, to resolve them; do it quickly; do it rapidly; and give the person the remedy the law has provided for them.

One avenue I feel very strongly about is, the Legislature should not criminalize the status of being HIV infected. It should not pass criminal statutes that are overbroad and underinclusive. By way of example: Pending legislation in the State of New Jersey varies from one extreme to another. Right now, we have a number of bills pending to upgrade and to make new criminal offenses. We want to criminalize blood donations. We want to criminalize the transmission of AIDS, in a knowing and purposeful transmission. However, what I don't think has been considered, is that a woman who is infected and gets pregnant, is knowingly transmitting it to her child. Do we want to criminalize, on top of the agony of suffering from this terminal illness?

We have overinclusive criminal statutes pending, which run the gamut from mandatory testing and fining for prostitutes and Johns, regardless of whether there is any sexual contact. For example, it would apply to a person who was trying to solicit a prostitute and, unfortunately -- or fortunately -- got an undercover police officer. There is no contact by which the transmission can be made one to the other. However, that person would be mandatorily tested.

One other area that I think is of critical importance is education. One way of trying to prevent the spread of the disease is education. We have not done that in this State. We have gone the other way, passing a thing which says that what we are going to teach children is abstinence, rather than recognizing the reality, which is that we need to teach not only that, but we need to teach ways of prevention. We need to teach safe sex if children -- or teen-agers -- are going to be engaging in it. We should recognize it, and we should encourage education.

ASSEMBLYMAN COLBURN: Excuse me. Have you seen the curriculum that the State Department of Education gives out to the schools, because I think what we passed about abstinence was simply an addition to what is being done? I don't think it was really supposed to supplant it. I saw that material a year or so ago down in Toms River, and boy, I'm telling you, it looked like a postgraduate course to me. I don't know whether you have seen that.

MS. STANLEY: It has been about a year since I have seen it.

ASSEMBLYMAN COLBURN: I guess the local boards probably have some say about what they do in their own districts, but the State Department, working with the Department of Health, really did come up with some rather extensive and specific material. I don't think we really eliminated that.

MS. STANLEY: I think it is very important, then, for that message to get out, because I think the message that is being received by--

ASSEMBLYMAN COLBURN: Well, maybe that was what came out in the press.

MS. STANLEY: --school boards, etc., is that that is the avenue they are to teach.

ASSEMBLYMAN COLBURN: Well, I must say, for myself, that I think abstinence should be something to think about and to promote. But on the other hand, if you are not successful with that, then you have to go the other routes, too. We don't want to preclude anything, I don't think.

MS. STANLEY: Exactly. I agree that you shouldn't preclude anything.

ASSEMBLYMAN COLBURN: I just wondered if you knew that material existed already?

MS. STANLEY: Actually, I do have it, but it's been a while since I have seen it.

ASSEMBLYMAN COLBURN: You know about that?

MS. STANLEY: Yes.

ASSEMBLYMAN COLBURN: Okay.

MS. STANLEY: Actually, just by way of updating the Public Advocate's statement, yes, the Department of Corrections did deem the Surgeon General's brochure on AIDS to be contraband in the State prisons.

ASSEMBLYMAN COLBURN: Did they? How about that.

MS. STANLEY: However, due to the constitutional implications of the denial, it is being distributed now to the State prisoners.

ASSEMBLYMAN COLBURN: I didn't think they would be able to do that.

MS. STANLEY: Thank you very much.

ASSEMBLYMAN COLBURN: Thank you. I saw you back there surviving this hearing for a long time.

MS. STANLEY: Very long. Thank you.

ASSEMBLYMAN COLBURN: Thanks a lot. Mr. Lampl, Executive Director, Hyacinth Foundation?

UNIDENTIFIED SPEAKER FROM AUDIENCE: He had to leave.

ASSEMBLYMAN COLBURN: Did he have to leave? Okay. Was there any material from him?

UNIDENTIFIED SPEAKER FROM AUDIENCE: I believe he submitted some material.

ASSEMBLYMAN COLBURN: Okay. Is it there someplace? (affirmative response) It is supposed to get to the Committee aides.

Delores Tyson, Family Planning? Oh, there you are. And, Ann Levine. There you are, okay. I met you in the elevator, and you're still here.

**D E L O R E S T Y S O N:** Yes, and we're still alive.

ASSEMBLYMAN COLBURN: I wonder if the elevator is still running. It might be disconnected by now.

May I ask who you are, sir? I met you in the elevator, too. I'm sorry.

**R O B E R T J A Y Q U I N N-O'C O N N O R:** I'm Robert Quinn-O'Connor. I am Assistant Director of the AIDS Services Expansion Program.

ASSEMBLYMAN COLBURN: Okay. My mind is getting boggled.

MS. TYSON: You have the testimony, and I will summarize it for you.

ASSEMBLYMAN COLBURN: Okay, thank you.

MS. TYSON: As you have already heard, there are 1126 women with AIDS in New Jersey, and tens of thousands who are HIV positive. Most of these women are of child-bearing age, and many of the children born to these women will develop AIDS and die.

Who is reaching these women, and how are they being reached? The family planning agencies in New Jersey have

entered into a cooperative agreement with the State Department of Health to become HIV counseling and testing sites for their clients. This is a significant step forward, since the majority of women at risk for HIV infection nationally are women of child-bearing age, exactly the population served by family planning agencies.

To date, there are eight family planning providers which have begun HIV testing and counseling in New Jersey. There are an additional 17 waiting for funding from the Federal government, in order to gear up to meet this crisis. Why this delay? CDC decided to discontinue two AIDS initiatives -- AIDS and Women, and AIDS and Minorities. In spite of this unconscionable decision, the New Jersey Department of Health managed 50% of the funds originally requested. HIV testing and counseling programs will be reduced in all family planning programs. These are programs that are ready to be implemented -- HIV testing and counseling -- with staff trained and systems in place, but they will be unable to be implemented because of funding shortages.

Funding cuts give rise to two specific problems:

Institutional barriers: Without funds, we cannot offer all services on demand or on-site. For some of us, this means that patients will have to be referred to an alternative test site. For others of us, this means that only one agency site can offer pre- and post-counseling or blood work. Transportation then becomes a barrier to obtaining the service, and the patient cannot, or does not follow through, and the original intent of the program is undermined. In addition, the patient is usually familiar with staff at the site commonly utilized. Going off-site means that she will have to go to an unfamiliar place and talk to unfamiliar people. Problematic, at best, with standard medical procedures; potentially tragic, when it comes to HIV infection.

Informational barriers: Funding cuts also impact on the ability of programs to do appropriate outreach and advertising, to ensure that the testing and counseling program is well-known and understood, as well as to educate the population at risk to the issues of AIDS and HIV infection. Again, unintentional though this may be, the purpose of the program is undermined, and success becomes elusive.

We must be able to operationalize our testing and counseling programs within family planning agencies, so that we can offer early diagnosis and proper treatment. We must be able to operationalize and enlarge our educational capabilities, to ensure that women and adolescents know how to protect themselves from acquiring HIV infection, so they live out their normal life spans.

What needs to be done? We must insist that women with HIV infection be once again made a national priority. We now take a step by calling for a Women and AIDS initiative in the State of New Jersey to lead the way. With this in mind, there are a number of bills relating to HIV infection and AIDS before your Committee. On the agenda today are two -- or were two -- A-2972 and A-3034, which would establish advisory councils or commissions to the Department of Health, one of which also provides a statutory basis for the newly created Division of AIDS.

We support the intent of the bills, but ask that representatives of service providers or advocates of preventive and early intervention services for women be included; specifically, the Family Planning Association of New Jersey and the New Jersey Women and AIDS Network. We urge that representatives of minorities and people with AIDS, or their advocates, be included, as well.

Now, Ann will make a few comments -- Ann Levine -- on the legislation just reported.

A N N E. L E V I N E: Yeah, now that we have seen the Committee substitute, Mr. Chairman.

ASSEMBLYMAN COLBURN: Right. Well, I didn't want you to raise too much of a fuss out there, you know, until now.

MS. LEVINE: I am going to, nevertheless.

ASSEMBLYMAN COLBURN: Well, go ahead.

MS. LEVINE: You know, we are very pleased that you included the minority and persons with AIDS representation. The problem with being so specific as to where the public members are coming from, is that you are automatically excluding people who really ought to be represented, like us, who are very large service providers of primary services, to a very large segment of the at risk population.

ASSEMBLYMAN COLBURN: One thing I think we might do, is get people to give us amendments that we might consider on the floor. After I did that, in my high-handed fashion, I listened to other people, and I thought that the Department of Health might be having some trouble with getting their relationships with the local people in order -- it would appear.

MS. LEVINE: Well, I appreciate that that would--

ASSEMBLYMAN COLBURN: Now, on the other hand, let me say this: Not every organization that receives money from these things, or every organization that is dealing with the people, can expect to be on that advisory commission. The reason I cut it off was, I just saw everyone justifying a position on the commission -- or the council, excuse me -- and I find that impossible. But we would entertain an amendment.

MS. LEVINE: I can see that that would be difficult, yes. But I would point out, as Mary Boland and other folks pointed out, that women, as compared to men, are--

ASSEMBLYMAN COLBURN: You know, I appreciate that; I think I appreciate that.

MS. LEVINE: I also did-- I'm sorry for interrupting you.

ASSEMBLYMAN COLBURN: .Another thing I wanted to say was, it is hard, I think -- and maybe I'm wrong -- in this situation, to be dealing with -- to set up whole separate mechanisms or buildings for a given group. I can see that women with children would need a certain location and all, but I think, to the best of our ability, we ought to try to make use of some joint facilities, at least with regard to the professionals involved. It almost sounded as though we needed a mechanism for this group and a mechanism for that group. I can see that it is hard to reach everyone the same way. I can appreciate that. But try to work it together, as best we can.

MS. LEVINE: Okay. Thank you very much.

ASSEMBLYMAN COLBURN: I'm sorry for giving you all of that testimony, but-- I guess I was out of order.

MS. LEVINE: I just want to point out that I did check with the sponsor about including family planning.

ASSEMBLYMAN COLBURN: I know.

MS. LEVINE: He had no problem with that.

ASSEMBLYMAN COLBURN: Well, I think-- When I spoke to him just before we did that-- I guess your conclusion may not have been the final one.

MS. LEVINE: Well, as I said, the sponsors had no objection. I don't know about the situation--

ASSEMBLYMAN COLBURN: Well, he kept thinking after he talked to you.

MS. LEVINE: Right. The only other thing I would suggest is, you might think about expanding the public-member segment to maybe around 25 or so, and not be so specific about the individual agencies.

ASSEMBLYMAN COLBURN: If you would submit some suggested language to us, I would appreciate it. Okay?

MS. LEVINE: All right. Thank you.

ASSEMBLYMAN COLBURN: Thanks a lot. You saw this release today? This is not from your group, but it's from

another group. Why don't you just take a look at it, and give it back to me?

MS. LEVINE: Thank you.

ASSEMBLYMAN COLBURN: Is Mr. Cunningham still here?

UNIDENTIFIED STAFF AIDE: No, but he submitted testimony.

ASSEMBLYMAN COLBURN: He gave us his testimony, okay. Is Mr. Driscoll still here? (no response) I don't know whom he was representing. Sue Dondiego? There she is. We thought you left. Okay.

**S U E D O N D I E G O:** Foster Parents are tough.

ASSEMBLYMAN COLBURN: They are, that's true.

MS. DONDIEGO: Thank you. A lot of what I was going to say has been said, so I would just like to say the reason I am here is to be another voice for children, especially foster children, because children usually end up on the bottom of the heap, and foster children are somewhere underneath that.

I think some of the things that have happened have been very good. But one of the things that we still need, that is not happening, is that foster parents who care for children with AIDS need some kind of combination orientation/training/support for them and their children. Everyone forgets that a lot of us have our own birth children when we are dealing with death and dying. Most of our children get very upset just with the ins and outs of regular foster children. When you are dealing with a child who very possibly may die, it is very important, and there isn't anything there now.

The other thing that has happened over the last few years, is that we work a lot with birth parents in regular foster care. In order to work with a birth parent, or parents, who have AIDS, we need more training, because lots of times they are denying that their child has AIDS, or that they are ill and cannot take care of that child themselves. What we are

saying is, we need more training. There is no funding for it, and I don't know where we are going to get it. That is important, if it is going to succeed, and if people are going to continue caring for children with AIDS.

The other thing they would like to see is support groups for foster parents, their birth children, birth parents, and the DYFS workers or others who are involved, maybe even in a particular case. Don't isolate everybody. Get them together so that everybody is hearing the same thing, and able to interact with one another. That is not happening, for the most part.

The other thing that there really isn't any funding for -- and I think there are still some reps here from the Department of Health, so maybe they would consider this -- is for foster parents to go to conferences that deal with AIDS, or to workshops, and things like that. We just haven't had any funding around. We did find some last year.

ASSEMBLYMAN COLBURN: Maybe within the State, do you mean?

MS. DONDIEGO: Well, what I'm hoping for is, maybe they will give us a couple of slots, that's all, just to send some foster parents.

ASSEMBLYMAN COLBURN: Oh, I see, okay.

MS. DONDIEGO: Last year we did. There was one foster parent who was caring for children with AIDS, and another who was thinking about it. We sent them up to the Hilton in North Jersey someplace. But they lived in Cape May County, and they had to stay overnight. The bill ended up being -- between registration and the hotel and giving them something to eat, babysitting, and mileage-- It came to about $600. Since we are already volunteers, asking someone to put that out is really asking a lot.

ASSEMBLYMAN COLBURN: Yes, that is significant.

MS. DONDIEGO: You have already heard this, but we did access to local pediatricians, dentists, and hospitals. There are some really good hospitals. But in the case of Mary, who was here before, Mary lives in Morris County, and it is hard enough as a foster parent trying to find anyone who will provide medical services, because foster children are on Medicaid, but to find someone who will truly care for a child with AIDS, or needs to be aware of it--

ASSEMBLYMAN COLBURN: Is it useful at all to make use of the Cooper Hospital designation for pediatrics? Does that help in South Jersey, or is it not close enough to everybody? It's in Camden.

MS. DONDIEGO: It's good. You have heard about St. Clare's a couple of times today, and that's good. What we are trying to do is develop what we are calling "satellite homes" that are near a hospital. But on the other hand, when someone is interested, and someone calls and says, "Yes, I would really like to care for a child with AIDS," you don't want to say to that person, "Well gee, you don't live within three blocks of a hospital, so we don't need you." We desperately need them. But that is when it gets difficult. So far, they have not minded going back and forth, but as you have heard, the figures-- I just tacked them on at the end of my written statement. I am not going through them. But, we are going to need many more foster homes. If we are going to reach out to find them, that is a problem. I don't know what the answer is.

ASSEMBLYMAN COLBURN: Okay.

MS. DONDIEGO: But that I did want to say to you. Respite care has already been mentioned; homemakers, day care, and even other child care -- just babysitting. We run into confidentiality. Normally, you can get someone to watch your foster children. Who do you tell that this child is HIV positive, because that is what most of them are?

The other thing is, you have to then make sure that you get someone who is capable of taking the precautions that are necessary. Even though they are not extensive with an infant, there are precautions, and that person has to know. There are not that many people out there who do know. Most of us try to help one another.

ASSEMBLYMAN COLBURN: You know, one of the things that has come up a couple of times, which I guess I am slightly sensitive about being a physician, is the care of the Medicaid patient. I don't think a physician who has to pay his expenses can afford to take care of people under the Medicaid fee schedule. One of the things I suggested to the Commissioner a year or two ago, was that they consider paying more for certain things than others; like, they couldn't get enough obstetricians for what they were paying. I suggested selective increases for obstetrical care. I think maybe in this instance, we ought to ask for more pay for taking care of an HIV positive patient than for the rest of the patients, because you really can't-- I don't think you can give the type of care that is needed in a situation for the money they're paying. You know, they went up to $12 a visit, from $9, I think, in our office. I, personally, wouldn't wish to take more money, because I am suggesting it. But I think to get other people fairly compensated, it might be an idea.

Then they talked about home health care and providing nurses for 16 hours a day, but if they have to send a physician in once in a while-- I know I made a house call once to someone with shingles about 15 miles away. I forget what they paid me, but, you know, I wasn't doing it for the money. So I think that maybe some special pay for certain things to address a problem might be a thought.

MS. DONDIEGO: I don't think they are looking for very ill children. What we are looking for is even just normal childhood-- Do they have a cold? You know, you have to be a

little careful, when you have an HIV positive child. If the fever is high, do you really need to get plugged into somebody?

ASSEMBLYMAN COLBURN: Yes, it might get worse.

MS. DONDIEGO: But at least have somebody locally who could advise you, yes.

ASSEMBLYMAN COLBURN: I guess I was asking you to make the suggestion. I am writing it down as your suggestion, okay?

MS. DONDIEGO: Okay. If you can do it, that's fine.

Hospices have been mentioned many times, but something else we would like to see happen -- and it is not exactly a hospice -- is where a mother and her child can really have a safe, clean place to live -- hospice, I think, does come at the end, and that is in my testimony -- when one or the other of them is really seriously ill. I know one time someone in DYFS told me that there was a 16-year-old girl they needed a home for. It was known that she had AIDS, and she had a baby. They were able to place the baby, but what do you do with a 16-year-old with AIDS? They really should have been kept together, but there isn't anything out there for people like that.

A couple of good things we are doing-- You have already heard about St. Clare's, so I won't say anything more. They are wonderful. The Advisory Committee you have heard about. Foster parents are represented on that -- the one Mary Boland and Marc talked about. That establishes a special provider rate for foster families, which is good, and is trying to plug them into as many services as possible.

Two things we are working on, with the combined effort of a number of people -- who are in my testimony, but I won't read them all here-- There is a 10-minute videotape being developed. It is on recruiting pediatric HIV foster homes and also a bit about pediatric AIDS for public education. There are going to be approximately 1500 copies distributed nationwide. There will also be a follow-up guide for discussion.

We, meaning the New Jersey Foster Parents Association, and some DYFS representatives and the National Foster Parents Association, are also, by praying a lot at night, because we have no funding for this, are going to produce two PSAs for pediatric AIDS and follow-up material.

ASSEMBLYMAN COLBURN: Public service announcements. I just figured that out.

MS. DONDIEGO: That's right, yes. So far, we are getting help from the private sector, and we hope to film next week. We're winging it.

That is mostly what I wanted to say. I think it has also been said before that one of the biggest problems is still attitude. I don't know what we can do about public education, but even Foster Parents is--

ASSEMBLYMAN COLBURN: Well, the involvement of more and more people in groups ought to help -- churches, and all of us. I think it is a gradual, constant process, myself. I don't know that the press-- Well, I'm sure they try, but, in a sense, they almost create more fear than anything else, at least in my judgment.

MS. DONDIEGO: But I know lots of foster parents who care for children who are HIV positive, who do not say they are doing it.

ASSEMBLYMAN COLBURN: Yeah, I can imagine.

MS. DONDIEGO: Mary, who was here today, is one of the exceptions. She will stand up, and say, "Yes, this is what I am doing."

ASSEMBLYMAN COLBURN: It takes courage.

MS. DONDIEGO: Yes.

ASSEMBLYMAN COLBURN: Thanks a lot.

MS. DONDIEGO: Thank you.

ASSEMBLYMAN COLBURN: Michelle Brunetti, are you still here? (no response) Edward Cox? (no response) Barry Moore and Elaine Ehrlich? (no response) Theodosia Tamborlane? (no

response) She was from the Bar Association. She left us information. It's getting easier. Jerome Platt -- Dr. Platt? (no response) Martha Chavis? (no response) It is getting easier than I thought. Ronnie Davidson?

**D R. R O N N I E D A V I D S O N:** It's not so easy. (laughter)

ASSEMBLYMAN COLBURN: There you go. You seem so well rested. I can't understand that.

DR. DAVIDSON: It's been a relaxing afternoon. I've been here, not at work.

ASSEMBLYMAN COLBURN: You could selectively screen out what you wanted to?

DR. DAVIDSON: Yes. I am Ronnie Davidson. I am the Associate Director for Continuing Medical Education at the Academy of Medicine.

ASSEMBLYMAN COLBURN: You were featured rather prominently in this Medical Society report, I think.

DR. DAVIDSON: Yes, we were, but that is kind of old stuff.

ASSEMBLYMAN COLBURN: Is it really, already?

DR. DAVIDSON: I will briefly go through this, because the Department of Health, Division of AIDS Prevention and Control, has expanded our programs significantly.

ASSEMBLYMAN COLBURN: Okay.

DR. DAVIDSON: I think it is important that the Committee be aware of exactly what we're doing, and why we're doing it, and how we're doing it, because we are trying to reach the primary care physician. I think we have 50 infectious disease physicians in the entire State, with almost 6000 people with AIDS. Obviously, it is terribly important that we develop a model, where we can try to have our primary care physicians in the State become case managers.

In 1984, we were originally funded by the Department of Health. They came to us, and asked us to use an existing mechanism we have in place at the Academy, which is our roving

symposia series. I will just briefly tell you about it, because it is told in great detail here in my written statement.

The roving symposia series is, we conduct well over 380 programs annually in the hospitals throughout New Jersey. I think we impact on approximately 105 hospitals. There is a person who reports to me in my office who does nothing but coordinate these programs. There are 300 topics.

When the Department of Health came to us in 1984, they said, "Can we possibly use this mechanism to develop a program where we could impact in the hospitals on the diagnosis and treatment of AIDS?" -- clinical management, as some call it. We went to Dr. Oleske, who became the physician consultant for the initial program. A curriculum was designed. I should say a "curricula." However, we tried to maintain consistency within the program. Slides were developed, and we enlisted approximately 20 infectious disease physicians in the State to work with Dr. Oleske to develop the curriculum, and then to agree to participate as the lecturers -- one-hour lectures -- in the hospitals throughout the State. I think there were initially 23. That was before I came to the Academy. That was the initial mechanism.

We have expanded the series; from 23 it went to 30. It is so successful, we probably get about-- Last year, I think we had 46 requests, but we could only deliver 30 lecturers. However, we do keep the list. We always assume that, with good faith, we will be funded, so we can say to our hospitals, "Be of good cheer, if we cannot serve you this year. We will come around next year, and we will take into consideration those people who have not been served -- those hospitals."

Incidentally, when we do have the lectures in the hospitals, in the case of AIDS, and we do not do this for all of the clinical areas -- the 300 other topics that we address -- we ask them to open it up to the entire hospital community.

We feel AIDS is a hospital community issue. This has been enforced by the Department of Health. They have asked us to look at it that way, and not to be quite so elitist in our approach to our continuing medical education. Of course, we buy into that completely.

Last year, when we tabulated up our annual report, we had impacted on over 1000 physicians and health care workers in these-- We are now up to 29 or 30 roving symposia annually on diagnosis and treatment. The State came back to us again-- I shouldn't keep saying "the State." The Department of Health came back to us again, and said, "We feel there is a terrible issue within the State on counseling and testing -- pre-counseling and testing, post-counseling and testing, and referring of the primary care physicians. They simply don't want to touch it. They don't want to do it. How do you feel about it?" When you listen to John Sensakovic -- who I think gave testimony as one of the first people here, after the Department of Health finished-- We went to John Sensakovic because it is my feeling -- or, I went to him -- that he is probably one of the most sensitive infectious disease physicians in the State, and we asked him to work with us on this very sensitive issue of counseling and testing for AIDS with the primary care physician, because in effect what we're saying is, "You are not doing it."

We have put together the curriculum. It has been approved by the Department of Health. We are ready to go. The final set of slides-- All of the slides are developed. There is consistency with every lecturer who goes out. We would like to think we could expand beyond the infectious disease community. However, at this point in time, we are still using infectious disease physicians as our physician lecturers. It is our hope and intention that within the next year or two from the primary care physicians we are educating, we can call forth a new faculty, and expand and expand and expand, always

impacting. We go to the State Medical Society meetings, and the county Medical Society meetings also.

The materials are expansive. The Department of Health is using many of our materials for their own programs that are not primarily for physicians, because what we do is establish the slides, the outline, all the mediating materials that go along with it. So, we are funded, and are working very closely, because we really do believe that their needs are our needs, and if we possibly can impact upon our physicians -- because we are the designated teaching arm of the Medical Society -- we will.

As we went on with our counseling and testing series, which was the second series, we found that the physicians were constantly calling the Academy, and saying, "Well now, you're telling us about the diagnosis and treatment. That is one lecture annually. You are giving us one shot at this counseling and testing. True, you will probably have reached 2000 physicians by the end of the year, but we have questions. You know that guy, John Sensakovic, who came in, or George Perez" -- who is on my faculty -- "or Dave Gocke" -- who is also on my faculty -- "we want to talk to them personally." Well, you know, these guys are pretty busy, and we can't have everybody in every hospital talk to them.

Then, we went to the Department of Health, and we said, "You know, it might be appropriate to establish an AIDSLINE," which would be a hotline where physicians and health care workers could call in with their particular problems, and we could try to access from our 900 physician speakers bureau appropriate people to deal with issues that are arising all the time.

Also, after listening to the person who testified about the foster parents, you know, we have programs that would be appropriate for some of these parents to attend. They are given in some of the developmentally disabled facilities and

some of the State's psychiatric facilities in the southern part of the State. They could be appropriate. That is what the AIDSLINE is for. If they called up with their particular need, we have a person who is funded, again, by the Division of AIDS Prevention and Control, who is our AIDS Education Program Manager, who is to effect linkages. Her role, her job, is to effect linkages. When someone calls in with a problem, we need to know how to-- We had a physician who had a diabetic, who said, "I don't know how to tell her to dispose of her needles, because she has just been diagnosed HIV positive." We then called one of our faculty, and said, "This is the problem. Can you either contact that physician, or send us something in writing that we can refer? Or, can you help us to implement policy?"

At this point in time, we are implementing policy, because we go to Diabetes Control, and they are working on that. But that is what the Academy is doing. We get approximately-- I think we are running an average of about 40 or 50 linkages, as we call them, monthly. We also produce a newsletter, where we announce every conceivable educational program. Anyone who is even remotely interested -- we try to get the community-based organizations -- can be on the mailing list of the AIDSLINE newsletter. So, we are trying desperately to meet the need. It is an appropriate forum for dissemination of information from the Department of Health, also. They come to us: "There isn't a day that goes by that we are not FAXed new information. Can you possibly somehow send this out through your networking system?"

That seems to be working very, very well. It is expanding. We started out with a mailing list of approximately 250, and we are well over 1000.

Our fourth program, which is, again -- and always -- funded by the New Jersey Department of Health, is an AIDS physician assessment. We assess 10,000 physicians throughout

the State -- the entire membership of the Medical Society. We had what we thought was a phenomenal return -- a 20% return. Well over 2000 people responded. The report, I think, is in the final form. It will be available to all who want to see it. However, the report, and the implications, are noteworthy.

We find, naturally, that physicians who have had AIDS continuing medical education are treating HIV positive or HIV diagnosed infections. We find that whose who have not, are not, and do not want to. We have been able to look at it as a very adequate needs assessment for the design of new physician education, as well as other health care provider programs. We have every indication from the Department of Health that we will continue this assessment annually. So we will be the only State in the United States that will be able to give clear evidence of the effect of our continuing medical education on the knowledge, attitude, and behaviors -- behaviors would translate into "practiced management" -- of our physicians.

It is quite extraordinary -- briefly, just to tell you -- that we found, and this is vital to the State, that only 13% of the physicians who responded to the physician assessment knew about the AIDS counseling and testing centers. We have now mailed information to every physician in the State of New Jersey through our AIDSLINE. We announce it to every person who calls in. Every linkage that is effected gets information on the counseling and testing centers. There is so much misinformation out there amongst those in your profession. It's sad, but it's true. That is my job. We are there to remediate the problem, and I think we will.

We have recently been funded, again by the Department of Health, to run some joint programs with the New Jersey Hospital Association. They were here, and they spoke about their initiatives. We will expand and continue the programs we have, using that roving symposia, which works. Every hospital in the State uses it; they are used to it. They do not pay for

these programs, so we just sock it to them. I mean, first come, first served. We go beyond the hospitals, too. We are working very closely with the Division of Developmentally Disabled, because we see enormous problems there, with the implementation of their (indiscernible). The psychiatric hospitals are so overburdened with the problems of AIDS, that I think John Sensakovic -- and I don't think he would like me to tell you this -- is now doing ground rounds on a gratis basis, because we do not have the funds to do it. However, he is more than willing. He is an awfully good sport.

So, there are physicians who are doing so much as a result of our funded programs because, perhaps, we are acting as cheerleaders. Our enthusiasm goes on. They feel good about what we are doing; they feel good that we are funded. They are working very, very closely with the State. Now we are preparing programs, and they are listed in my statement. We are going to do three statewide major symposia on counseling and testing again and the availability of clinical trials on a statewide basis.

I want to mention just one more thing about the hospital-wide initiatives. It is our hope that we will impact on 100,000 hospital workers. When the Hospital Association and the Academy finish up at the end of one year, we would like very much to be able to document that. We are also going to work with the families of those health care providers who are working with the patients, because we feel that a lot of the attrition that is occurring within the profession, is a result of the pressure coming from their homes. It goes beyond just the health care worker.

I just wanted to share this information, and reenforce what we are doing with the Department of Health, and how very important it is that we continue. We really believe that our work is substantial, important, creative, new, and innovative. I just came back from California, from a meeting of all the

continuing medical educators in the United States. Nobody has the support of their state or their department of health such as the physicians and the health care providers in New Jersey have -- anywhere in the United States, as far as we can see. We are presenting papers that are going all over. We know of three states in the United States that are using the Department of Health programs that we are doing, as models.

ASSEMBLYMAN COLBURN: I guess when you send this -- what was it, the mobile--

DR. DAVIDSON: The roving symposia, we call it.

ASSEMBLYMAN COLBURN: --the roving lecturer around, or whatever you call it, they get CME credit for that Category I?

DR. DAVIDSON: Yes, that is Category I, Continuing Medical Education. I would like to say we are giving nursing credits, but unfortunately the nursing profession has made it very, very difficult for anyone who has tried to do that.

ASSEMBLYMAN COLBURN: So, they would attend the same lecture, but not get the credit?

DR. DAVIDSON: They don't get the credit. But we encourage all of the hospitals to open it up to their entire community, because we don't see how you can conceivably implement a system of universal precautions, unless you work as a team within the hospital.

ASSEMBLYMAN COLBURN: Yes, that's true. Let's see, what else was I going to ask you? Oh, I think almost every hospital would have an infectious disease physician, would they not, and if not, a nurse?

DR. DAVIDSON: Yes. Well, we work directly with the infection control nurses.

ASSEMBLYMAN COLBURN: I don't see Dr. Topiel's name on this list of physicians as resources. He is the infectious disease doctor at Burlington County. Do you have him on any list?

DR. DAVIDSON: No, I don't.

ASSEMBLYMAN COLBURN: Maybe he didn't volunteer, but I am just wondering?

DR. DAVIDSON: No, he didn't.

ASSEMBLYMAN COLBURN: Now he's got an associate with him, too, so try him again.

DR. DAVIDSON: Where is he?

ASSEMBLYMAN COLBURN: He's in Burlington County Memorial -- the Memorial Hospital of Burlington County.

DR. DAVIDSON: It's very difficult for us to find infectious disease physicians in the southern part of the State.

ASSEMBLYMAN COLBURN: Well, they are at every hospital.

DR. DAVIDSON: Well, they're at every hospital, but--

ASSEMBLYMAN COLBURN: But they won't go where?

DR. DAVIDSON: They won't go to the other little, tiny hospitals, that are very much in need.

ASSEMBLYMAN COLBURN: Like Elmer, for example, or Cape May Court House, or someplace like that.

DR. DAVIDSON: Exactly. But what we do, through the AIDSLINE, is try to effect linkages. If we know that we are running programs in a hospital with a very small staff, we send out notifications to surrounding hospitals, saying, "Please be aware that this program is occurring within your geographical locale. Send someone from your hospital." But we can only do as much as people call out to us to do. We try to be as pro-active as possible. However, you know, we are in a reactive stance, and we are limited by our resources and the people we have to do it. Anyone who calls -- that is our agreement with the Department of Health-- We have to document every call that comes in, and give an indication of exactly what we did.

ASSEMBLYMAN COLBURN: Are there many physicians, do you think, who are not in the Medical Society or the Osteopathic Society or not on a medical staff? Do you have any idea how many there might be?

DR. DAVIDSON: I think there are approximately 12,000 physicians in the State of New Jersey, and we hit 10,000.

ASSEMBLYMAN COLBURN: Well, there used to be 9000 in the Medical Society of New Jersey. I don't know what it is now.

DR. DAVIDSON: Well, it's probably about 9500. A lot are retired, and then, a lot are students. However, we are desperately trying to get students into our programs, because if we can possibly change their, as we said, knowledge, attitude, and behavior, you know, right at the very initial entry into the profession, we are far better off.

ASSEMBLYMAN COLBURN: How many osteopaths in their Society, do you know? Do you cover that Society? You don't, do you?

DR. DAVIDSON: No, we don't, although it is open if they are affiliated with a hospital.

ASSEMBLYMAN COLBURN: I know they can join the Medical Society, but I don't think the Academy services them, as their educational arm, do they?

DR. DAVIDSON: No, but we are wide open to osteopaths within the Academy as fellows.

ASSEMBLYMAN COLBURN: Okay, I recognize that. If they want to join--

DR. DAVIDSON: On my Advisory Board, I have an osteopath, who is looking over my shoulder all the time. So it's his role, because my position is regulated by an educational committee -- an Advisory Board of physicians.

ASSEMBLYMAN COLBURN: It's a good thing.

DR. DAVIDSON: Do you think so?

ASSEMBLYMAN COLBURN: Sure.

DR. DAVIDSON: Well, I am an educator; I am not a physician.

ASSEMBLYMAN COLBURN: I've had a tough time controlling you here this afternoon.

DR. DAVIDSON: But I hung in there. Thank you very much.

ASSEMBLYMAN COLBURN: Thanks a lot. We appreciate your coming here.

DR. DAVIDSON: Surely.

ASSEMBLYMAN COLBURN: Let's see, who else has survived? Caren Linder? (affirmative response) Oh my gosh! Good for you. You're even smiling. You're a survivor. We did have another social worker. It wasn't in his title, but I read it in the substance of his testimony somewhere. We may have had others, but I don't know who they were. So, you might be almost unique.

**C A R E N L I N D E R:** Okay. Thank you very much for your time today.

ASSEMBLYMAN COLBURN: Well, thanks for sticking it out.

MS. LINDER: My name is Caren Linder. I am an MSW and work with the HIV Testing and Counseling Program at the Planned Parenthood Association of the Mercer Area -- PPAMA. I am here today to express my concerns regarding lack of funding for HIV services for women.

As you well know, the CDC has cut the amount of funding for AIDS. New Jersey has had to fight to get just half of its initial request. As someone who provides direct services, I find this very disturbing, as New Jersey has the fifth highest number of AIDS cases in the nation. Even more alarming are the facts that New Jersey has the highest percentage of AIDS cases for women -- 20% -- as opposed to 8% nationally; the second highest rate of pediatric AIDS cases in the country; and in New Jersey AIDS has become a leading cause of death in children, and for women aged 25 to 34.

Among the women with AIDS in New Jersey, 67% are black, 9% Hispanic, and 23% white. Often women are introduced to the virus unsuspectingly through their intravenous -- IV -- drug-using partners. Many women are unaware that they can

become infected. In addition, there are men who have had unprotected sex with men who then have unprotected sex with women. All these factors put women at high risk of HIV infection. These factors put our 7200 patients and our clients at risk. Every day I see women who tell me they were ignorant of the fact they are at risk for HIV, believing the myth that AIDS only affects gay men and IV drug users. They then proceed to tell me about IV drug-using partners, bisexual partners, and partners who have been in prison, where a significant amount of high risk behavior occurs.

ASSEMBLYMAN COLBURN: Excuse me. What is their response when you tell them these things? Do you think they are going to change what they do as a result of learning this?

MS. LINDER: Usually they learn about HIV when they are in the clinic downstairs. Then if they seem to be at risk, they are offered HIV testing, and they can see me. When I ask them, you know, how they think they may have become infected with the virus, they are really not sure.

ASSEMBLYMAN COLBURN: You are seeing them after they are positive only. Is that correct?

MS. LINDER: No. I do the pretest and post-test counseling.

ASSEMBLYMAN COLBURN: Okay.

MS. LINDER: I see them if risk seems to have been identified when they were in the clinic for annual exams, or any sort of exam.

ASSEMBLYMAN COLBURN: So they are a selected group to start with.

MS. LINDER: Or, it is offered to everybody who comes in.

ASSEMBLYMAN COLBURN: I was just wondering. By receiving this information from a person who knows what she is talking about, I wonder if they change their behavior?

MS. LINDER: Usually, they don't think they are at risk. Then when I tell them they can get it from their partners, and they tell me the behavior of their partners, usually their faces just drop. They get really scared and panicked.

ASSEMBLYMAN COLBURN: Is there any way to check up on what they then do later?

MS. LINDER: Well, when they come back for post-test counseling, to get their results, I have an opportunity to speak with them.

ASSEMBLYMAN COLBURN: And you speak with them whether they are negative or positive?

MS. LINDER: Yes, I am the only one who speaks with our patients regarding HIV, really. They get education downstairs, but in terms of the testing and counseling program, I'm it.

ASSEMBLYMAN COLBURN: Okay.

MS. LINDER: Of the 7200 women PPAMA serves each year, approximately 90% are low income, 70% single, 40% minority, and 80% have multiple partners -- the population at greatest risk of HIV infection through heterosexual contact. Only education about transmission of the virus and risk reduction behaviors can stop the spread of HIV infection and AIDS. We have estimated that the cost of a well-run, effective HIV testing and counseling program would cost $103,490 per year. However, because of the CDC funding cuts, our facility was granted less than $30,000 to run this program. We are doing our best, but we cannot provide intensive education and counseling to all of our patients or their partners regarding the transmission of the AIDS virus and how to reduce their risk of contracting the disease.

It is essential that we be adequately funded to reach this high risk population. Family planning clinics are oftentimes the primary health care provider for the people we

serve. Women use our clinics for family planning as well as STD treatment -- a significant indicator of HIV transmission. The women who utilize our clinics have built a relationship of trust and good rapport with our clinicians. The foundation has already been laid from which we can provide education, counseling, prevention, and risk reduction services. However, in order for our clinics to function effectively as a source of such services, we must have additional staff. We cannot provide access to these lifesaving efforts without the trained professionals. I am the only person providing counseling for the five PPAMA clinic sites. We see over 7200 family planning patients a year, and provide services for over 200 prenatal clients each year; critical groups of women to whom we must provide services if we are going to stop the overwhelming incidence of HIV positivity in women and their children. We are losing the opportunity to reach out to and provide services for our clients because I am faced with an impossible task of being at five clinic sites at once.

Another significant factor in having HIV testing and counseling offered at family planning clinics like ours, is to allow women to make good decisions about their bodies. Women who have received education, counseling, and then, if they choose, testing, will know their serostatus and can take it into consideration when making decisions about their sexuality, contraception, and childbearing.

As of December 1988, the number of infants born with HIV in New Jersey was 5688, an extremely upsetting and unacceptable figure. The only way to even begin to address this issue is to educate the women who receive services at family planning clinics before they choose pregnancy.

The other day, I met with a woman who has been happily and anxiously awaiting the birth of her first baby. She had recently discovered that her partner is HIV positive. Watching her go through the anguish, despair, confusion, and sadness

over what this might mean for her baby and herself, was one of the saddest human experiences I have ever witnessed.

The realities I see every day are very harsh. Additional funding will not alleviate the AIDS virus or the disease itself. However, dollars can help us prevent additional women and their infants from becoming infected. These dollars will enable staff at family planning and prenatal clinics to provide education, counseling, testing, and support services to the much denied and often forgotten group of individuals at high risk for HIV infection: the women in New Jersey, specifically minority and low-income women. New Jersey has the highest rate of HIV positive women in the country. We provide a pap test and breast exam for all of our patients. The very least we can do for the citizens of New Jersey is to provide basic HIV-related education, medical, and support services for women and their children.

ASSEMBLYMAN COLBURN: Thank you. Right now, I don't know that I can think of anything else to ask you, partly through an atrophy of the brain, at this moment.

MS. LINDER: Understandable.

ASSEMBLYMAN COLBURN: Thanks a lot.

MS. LINDER: Thank you.

ASSEMBLYMAN COLBURN: Reverend Davidson? I think I have figured out who you are here.

**REVEREND BRUCE H. DAVIDSON:** How about that? By the process of elimination. I am the appropriate person to call up when speaking about atrophy of the brain, too. (laughter)

ASSEMBLYMAN COLBURN: I think I need help.

REVEREND DAVIDSON: That might be two of us.

ASSEMBLYMAN COLBURN: You're from North Jersey somewhere?

REVEREND DAVIDSON: Yes, Bergen County -- Teaneck. I have copies of what I had prepared, but am probably not going to completely say.

ASSEMBLYMAN COLBURN: Fine, okay. Well, if you want to, you can.

REVEREND DAVIDSON: I know, but I--

ASSEMBLYMAN COLBURN: You are the last one.

REVEREND DAVIDSON: --think some of this will be--

ASSEMBLYMAN COLBURN: Except for the hearing reporter, who has suffered through all of this. The rest of us are expendable.

REVEREND DAVIDSON: Okay. I appreciate the opportunity to testify and all the patience all of you have shown.

ASSEMBLYMAN COLBURN: Well, thanks for coming down here. We do things in large doses in this Committee.

REVEREND DAVIDSON: I guess you do, yeah.

ASSEMBLYMAN COLBURN: We don't do much for a long time, and then all of a sudden we do a lot.

REVEREND DAVIDSON: You get hit with it.

ASSEMBLYMAN COLBURN: Yes.

REVEREND DAVIDSON: Well, it's pretty overwhelming.

ASSEMBLYMAN COLBURN: We have taken on a few other formidable subjects.

REVEREND DAVIDSON: I imagine so.

What I would like to do is read the first part of this statement that describes the Interfaith Network more succinctly than I probably could do it, and then I would just like to comment on the issues we have raised, because a lot of them are redundant. But I do want to let you know that this comes from a religious community gathered together to respond, in some fashion, to people with AIDS.

The AIDS Interfaith Network of New Jersey is now in its second year of existence. In its short history, the Network has brought together clergy and laypeople from Jewish, Roman Catholic, Protestant, and Islamic faith communities. We have attempted to learn more about AIDS and the many ways in

which it affects people. In doing this, we have met with a variety of people throughout the State in a variety of locations and settings, including hospitals, care facilities, and drug treatment centers. Because we hope that our learnings will help us develop ways to put our compassion into action, an Action Council has been formed as part of the Network. This Action Council brings together designated representatives of Conservative and Reform Jewish communities, official observers from four Roman Catholic dioceses in New Jersey, and individuals representing the following Protestant communites: Baptist, Lutheran, Presbyterian, Episcopalian, United Methodist, United Church of Christ, the Assemblies of God, and the Society of Friends. In addition, the Action Council includes a representative of the New Jersey Council of Churches, an ecumenical organization including 16 denominations.

Needless to say, this is a very diverse group of people with a wide range of theological understandings. However, there is one very strong element that holds us together. In all of our faith traditions, compassion and concern for the sick and the suffering is a central moral imperative. In this our faith communities agree: When faced with serious illness, people of God are called to respond with compassion and loving service toward those affected by disease.

One of the major aims of the Network is to enable those who are living with AIDS, their families, and friends to benefit from the resources of the religious community. Another is to mobilize the religious community and the community at large to become involved in efforts to cope with the AIDS crisis.

Now, the concerns I would like to mention that we have identified, and this is as a result of some of our experiences-- First of all, we join others in saying there is a tremendous need for continuing education. We don't see education as a panacea. We don't think that is going to make

the problem go away, but we do feel that it will do a couple of things.

One, we think it will help to alleviate some of the panic and hysteria; and secondly, we think that with education, some people are likely to develop a much more compassionate response and get involved.

I was interested in hearing what people said about doctors who received education, and then their ability to go out and minister in ways that they hadn't before, and I think that is telling.

ASSEMBLYMAN COLBURN: It's true.

REVEREND DAVIDSON: Yes. The other thing we think education will do is help people to understand how they can avoid getting the disease. The more factual education the people seem to have-- It does make a difference, we think, in the way they will respond.

The second thing we identified as a reason for concern is the spread of AIDS, especially in the city and among black and minority populations. We are tremendously concerned, as others have been, with finding out how poor the drug treatment facility situation is, especially for those who do not have financial resources. We were shocked and more than a little appalled at the fact that someone who is poor, living in the inner city, would have a very difficult time getting any kind of treatment. We feel this is going to be very serious in terms of controlling not only the drug problem, but also the spread of AIDS. We hope that something can be done about that.

Finally, we are hoping that we can increase the number of facilities that are available for people, both long term and short term, who need care, and who need assistance in functioning, living, and dealing with the illnesses they face. We know there is a problem sometimes in establishing care facilities for people with AIDS, and we want folks to know that the churches and the clergy are available to help make it

possible, in some communities, for facilities to be established. I would point out that in Wanaque, for instance, the Network was involved in trying to mobilize clergy to get the message out to church people that it was okay for this facility to be in the community, and I think it was helpful, and to stand and say that we are available to do that again.

ASSEMBLYMAN COLBURN: We appreciate that.

REVEREND DAVIDSON: Okay. A couple of other quick things.

ASSEMBLYMAN COLBURN: I didn't think you had finished, but as soon as you are, I am going to keep you going a little longer.

REVEREND DAVIDSON: Okay, fine. Just a couple of other quick things I would like to address. One is the issue of confidentiality, and it has been talked about over and over again. I would just like to share my own personal experience with that. In spite of legislation that is on the books already, there are still instances of people who are discriminated against in housing and in employment, because of having AIDS.

ASSEMBLYMAN COLBURN: Resulting from lack of confidentiality?

REVEREND DAVIDSON: Exactly right. I have seen copies of leases that are legal because they somehow fall under the legal limit of the number of units you have to have to comply with the code. One at least specifically spelled out is, if a person has AIDS, they would be immediately evicted, and would be responsible then for having the entire facility santitized, for steam-cleaning the rugs, etc.

ASSEMBLYMAN COLBURN: How many units?

REVEREND DAVIDSON: It was one unit. It was a two-family kind of thing.

ASSEMBLYMAN COLBURN: In somebody's house, or something?

REVEREND DAVIDSON: Well, it was an adjoining property, basically.

ASSEMBLYMAN COLBURN: Like a double house, or--

REVEREND DAVIDSON: Yeah, on one parcel. Less than three units. I guess that is of concern to me because in Bergen County, we have a tremendous problem in terms of people finding any kind of housing at all.

ASSEMBLYMAN COLBURN: Yes.

REVEREND DAVIDSON: If someone finds himself in need of a place to live, he needs to exhaust all possibilities. To know that for a person with AIDS, they are going to be even more restricted than the normal person-- That is a serious problem and issue.

The other thing I guess I want to comment on is, I helped to facilitate a group that is of support for families of people with AIDS. Not only is there discrimination against PWAs, but there is discrimination against families, as well. I could tell you some stories about people who have had their employment in jeopardy, simply because someone in their family was infected. I think that until that question of discrimination and hysteria can be resolved better than it is now, to talk about letting people be tested without the cover of confidentiality is irresponsible.

The other thing I guess I would say, that hasn't been mentioned, is that even if somehow successfully we can protect people with AIDS from discrimination in employment and housing, it occurs to me that for some people who come back with a positive test result, that will not only reveal their health, it will also reveal their sexual orientation. People who are gay and lesbian in the State of New Jersey have no civil rights protection in housing and employment. So I can see a situation where a person might be able to stay in his or her job even though they had AIDS, but be dismissed because they were gay or lesbian. Again I feel that that is another reason to maintain confidentiality, at least until those issues can be resolved.

ASSEMBLYMAN COLBURN: Were you here when several black people testified that they felt their groups were not being properly treated by the State Health Department?

REVEREND DAVIDSON: Yes.

ASSEMBLYMAN COLBURN: One reason I put people lower on the list from some of the groups that were receiving funding was, I figured some of them would be coming up kind of having something to say about individual funding for their particular organization. I wanted to try to lead off with a more general knowledge about the subject and what we are doing.

REVEREND DAVIDSON: Makes sense.

ASSEMBLYMAN COLBURN: But on the other hand, if, in fact, they were saying something that was accurate, it bothers me, you see, because I think as far as I know, the black church is pretty much an important part of the fabric of the community.

REVEREND DAVIDSON: Absolutely.

ASSEMBLYMAN COLBURN: Whether they always do a perfect job or not, and everything, I don't know. I am not prepared to say. But it seems to me that we ought to try to make use of them in dealing with this--

REVEREND DAVIDSON: I would say so. I think that is very important.

ASSEMBLYMAN COLBURN: --thing and communicating with the rest of the black people.

REVEREND DAVIDSON: Absolutely.

ASSEMBLYMAN COLBURN: Maybe they don't influence all of them.

REVEREND DAVIDSON: No, but they have a significant -- a very significant impact.

ASSEMBLYMAN COLBURN: They are, I think, very important in their communities. They meet on every subject. They have political candidates talking to them, which I have never done, but--

REVEREND DAVIDSON: You bet. And there is a support and a caring network that is there that is extremely important. It should be taken seriously.

ASSEMBLYMAN COLBURN: I think we ought to try to really make use of that.

REVEREND DAVIDSON: I think that is very true.

ASSEMBLYMAN COLBURN: Are we going to look into that further, I hope, to try to reach some conclusion that is appropriate?

**A S S T. C O M M. R O B E R T F. H U M M E L:** (speaking from audience) I think that issue has been around since the beginning of this epidemic. It was very difficult in the early years of this epidemic to get the churches, because of the origins of the disease -- the gay behaviors and the drug behaviors--

ASSEMBLYMAN COLBURN: Yeah, that's right, to get people to mingle with those other people.

ASSISTANT COMMISSIONER HUMMEL: We clearly have made it a priority; obviously, in some people's minds, not enough of a priority.

ASSEMBLYMAN COLBURN: I think we have to straighten that out somehow, and get some trust going.

What else was I going to-- There was something else I wanted to mention.

REVEREND DAVIDSON: I have one other -- actually two other things I want to bring up. One is, I want to join the list of those people who -- not me personally, but I think the religious community--

ASSEMBLYMAN COLBURN: Be on the Advisory Council?

REVEREND DAVIDSON: I think the religious community should be among those who were identified as being important to involve. There was no representation from the religious community. Again, I think we can be an important and significant ally--

ASSEMBLYMAN COLBURN: I agree with you.

REVEREND DAVIDSON: --particularly in matters of education. We do have a message of compassion, with which we, I think, can help to raise people's awareness a little bit.

ASSEMBLYMAN COLBURN: Another thing I think, too, is, to me, I have seen an awful lot of the stress placed on safe sex.

REVEREND DAVIDSON: Right.

ASSEMBLYMAN COLBURN: You know, that is all well and good, but, by golly, there are some other standards that we could adhere to if we were convinced that they would get us through this thing. We have the knowledge to stop this cussed thing. Back in the time of the bubonic plague, they didn't know where it all came from. We know, and by golly, it seems to me that the point of view that you might wish to at least endorse, ought to be heard.

REVEREND DAVIDSON: I would hope so. I think also, you know, in terms of some other ethical questions that will come up, it would be helpful to have representatives from religious communities.

ASSEMBLYMAN COLBURN: Yes.

REVEREND DAVIDSON: I was caught early on in the hearing today, when I believe you raised the question about whether or not it would be better policy to cut back on people receiving AZT, so that we could--

ASSEMBLYMAN COLBURN: Educate more.

REVEREND DAVIDSON: Yes, educate more people, so that less people would come down with AIDS. To me, that is an ethical issue.

ASSEMBLYMAN COLBURN: Yes, it's a tough one.

REVEREND DAVIDSON: I think the way you left it was to suggest that the legislators would have to make that decision. I would certainly hope they would do that in consultation with some ethically--

ASSEMBLYMAN COLBURN: You mean that they would appropriate the money, don't you, for some of this?

REVEREND DAVIDSON: Well, okay, that could be the case.

MR. COX: It is going to be up to the legislators to--

REVEREND DAVIDSON: To appropriate the money.

MR. COX: To appropriate the money, yes.

REVEREND DAVIDSON: I think that one has some very frightening consequences.

ASSEMBLYMAN COLBURN: Well, believe me, as a physician, I hate to see the treatment cut back.

REVEREND DAVIDSON: Yes, I was aware of the citation.

ASSEMBLYMAN COLBURN: They will have a hard time with me over that one.

REVEREND DAVIDSON: Okay, good.

ASSEMBLYMAN COLBURN: It's not only with AIDS they are talking like that. I hear in England, that you don't get dialysis when you are past a certain age, and that is to conserve funds. I mean, our national health budget is so big, that they are talking about rationing.

REVEREND DAVIDSON: Oh, yeah.

ASSEMBLYMAN COLBURN: One thing I was going to mention to you is, when we, as county officials, were dealing with Federal programs, we had one heck of a time with the changing regulations and all the things that would come to us that we couldn't understand. Or, if we thought we understood them, we would send them back, and the agency would tell us we did it wrong. So when those black ministers, or whoever they were, came in and said they had done the thing wrong, you know, they sent the cussed thing in and it came back-- I can sympathize with them.

REVEREND DAVIDSON: Oh, yeah, sure.

ASSEMBLYMAN COLBURN: I think when it comes to things like that, you know, those darned paperwork kinds of things, we ought to be helping people to get through that, instead of--

If it is used as any kind of a filter, or in any way that is obstructionistic-- I don't know. I'm sensitive about that paperwork, so please do what you can to simplify it. We know that you hire a grant writer and they know the buzzwords. I don't know about the State, but with the Federal, you have to hire a grant writer to write the right words and the cussed application--

REVEREND DAVIDSON: Sure. We have had that experience all right.

ASSEMBLYMAN COLBURN: --and the darned thing gets approved. You know, you have to hire a consultant. We did that at the county, because we didn't know how to write those stupid things.

REVEREND DAVIDSON: They're intimidating. I mean, I--

ASSEMBLYMAN COLBURN: Oh, they scare the living daylights out of you.

REVEREND DAVIDSON: They do out of me, I know.

The final thing, I guess, that I would just like to say, is that we have had some very positive experiences, both the Network and individual churches, with the Department of Health -- the AIDS Division.

ASSEMBLYMAN COLBURN: Well, in spite of everything we say, they are really a good group. We are just trying to make them better.

REVEREND DAVIDSON: We have been favorably impressed. We have gotten a lot of good, helpful information. There has always been an immediate response to requests for speakers and information. That has helped us to get off the ground, so we appreciate that.

ASSEMBLYMAN COLBURN: Fine. I hope their resources can be increased. I don't know. The budget is tough this year, they say.

REVEREND DAVIDSON: Right. Thanks again.

ASSEMBLYMAN COLBURN: Thank you very much.

We are going to close now. Does anyone wish to say anything -- anyone who has stuck it out all this time? (no response) Okay, thank you. We will adjourn this hearing.

**(HEARING CONCLUDED)**