
Public Hearing

before

ASSEMBLY HEALTH COMMITTEE
and
**ASSEMBLY POLICY AND REGULATORY OVERSIGHT
COMMITTEE**

“Public input regarding how the State can implement the recommendations of the Breast Cancer Summit held on May 12, 1995, as outlined in the formal findings report”

LOCATION: Auditorium
Bergen Pines County Hospital
Paramus, New Jersey

DATE: October 16, 1996
1:00 p.m.

MEMBERS OF ASSEMBLY HEALTH COMMITTEE PRESENT:

Assemblywoman Charlotte Vandervalk, Chairwoman
Assemblyman Nicholas R. Felice, Vice-chairman
Assemblywoman Barbara W. Wright
Assemblywoman Arline M. Friscia
Assemblywoman Loretta Weinberg

**MEMBERS OF ASSEMBLY POLICY AND
REGULATORY OVERSIGHT COMMITTEE:**

Assemblywoman Rose Marie Heck, Chairwoman
Assemblyman Kevin J. O’Toole
Assemblyman LeRoy J. Jones Jr.
Assemblyman William J. Pascrell Jr.

ALSO PRESENT:

David Price
Katharine A. Tasch
Office of Legislative Services
Aides to the Committees



Hearing Recorded and Transcribed by
The Office of Legislative Services, Public Information Office,
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ASSEMBLYWOMAN ROSE MARIE HECK (Chairwoman, Assembly Policy and Regulatory Oversight Committee): We are going to begin by introductions of both of our Committees. I will introduce the two members of my Committee who are here: Roy Jones, to my right -- Roy, just wave -- and Kevin O'Toole. We are members of the Assembly Policy and Regulatory Oversight Committee. I think Assemblyman Pascrell will be showing up soon.

Charlotte will introduce the members of the Assembly Health Committee.

ASSEMBLYWOMAN CHARLOTTE VANDERVALK (Chairwoman, Assembly Health Committee): Thank you.

Starting at the far left, we have: Assemblywoman Arline Friscia, Assemblywoman Loretta Weinberg, and Assemblywoman-- I am stumbling because we have all these women.

ASSEMBLYMAN FELICE: Don't rub it in.

ASSEMBLYWOMAN VANDERVALK: Assemblywoman Barbara Wright, Assemblyman -- we will allow you -- Nicholas Felice, and myself, Charlotte Vandervalk.

Welcome, all of you.

ASSEMBLYWOMAN HECK: I am going to begin with some opening remarks, followed by Charlotte. Then I will introduce the CEO of Bergen Pines, Ed Louis, and Joan Wright, of course, Chief Operating Officer of Bergen Pines. I just want you to know how we are going to move on this.

Today, we are going to hear from the front lines, the women and men in the medical profession in breast cancer awareness advocacy, and those who work with survivors, about what New Jersey needs to fight breast cancer.

New Jersey ranks third in the nation in breast cancer mortality rates. To me, this is frightening. I thank the sponsors of the 1995 Breast Cancer Summit. We know that our State ranks very high in mortality rates and with the incidence of breast cancer compared to other states. They have given us wonderful information. The members of that Summit include: the American Cancer Society, New Jersey Division, the New Jersey Commission on Cancer Research, the New Jersey State Department of Health, The Cancer Institute of New Jersey, and The Medical Society of New Jersey.

These sponsors of the Breast Cancer Summit help the 7000 women who learned, last year, that they had breast cancer. The Summit participants are helping the families cope with the diagnosis of breast cancer. And you are helping us in the Legislature to designate strategies for diagnosis, prevention, and, hopefully, the identification of a cure.

I thank my colleague and friend, Assemblywoman Charlotte Vandervalk, for holding this special joint hearing with my Committee to address how to help New Jersey women of all ages and races fight breast cancer.

Thank you, Charlotte, for holding this hearing during Breast Cancer Awareness Month. We really worked at this.

We need senior citizen women who are 65 and older to participate in getting their mammograms. Only 40 percent of the women seen by physicians participating in an American Cancer Society survey had been

recommended to receive mammograms. That number must go up. We want to make certain that all women have access to mammography information for health and breast screening. We must work to increase the percentage of Medicare reimbursement from the 31 percent figure for New Jersey women. We are below the national average, and have the second lowest utilization in the entire country. That is unacceptable to us.

According to the Summit report, Bergen County ranked first in the number of breast cancer cases of all races from 1985 to 1991, a total -- a shocking total -- of 5146 cases. Essex County followed a close second, with 4209 cases, and Middlesex and Monmouth Counties ran a close third and fourth in the ranking. Bergen County had the highest mortality count county by county, for black and white women. One hundred eighty seven women died. Essex followed with 148 women dead, and Ocean with 137 dead.

We have a big problem in New Jersey. Let me mention the Breast Cancer Checkoff which was sponsored by myself and former Speaker, Chuck Haytaian, and cosponsored by Charlotte, that was signed into law by Governor Whitman. This fund will help to supply critical dollars to a much needed research fund to help to find a cure for breast cancer. The Checkoff to be implemented for this coming tax year will absolutely save lives. We have just found out that it is number 55. That is the line we have on the income tax return. So think in terms of 55 miles an hour -- as Judi said to me (speaking of Judi Klein, an upcoming witness) -- and the age of 55 and over, women who must have checkups made and who must conduct self exams.

Both legislative Committees will be listening closely today, as we identify the way in which to enact the critical recommendations of this public

policy Summit. We have our ideas on which policies to implement, but we want to make certain that we are on the right track with the Breast Cancer Summit sponsors. It is very important for you members of the Summit to give us that information. Also, we will hear from breast cancer survivors, as well as their advocates.

Special thanks to the New Jersey Breast Cancer Coalition for its leadership in the pursuit of a cure, and to the women and men who serve on the Advisory Group for the New Jersey Breast Cancer Research Fund. All of you are advocates who make a difference every day, and I applaud you.

I am going to turn the mike over to Charlotte, who has some opening remarks as well.

ASSEMBLYWOMAN VANDERVALK: Thank you.

I really just thank everyone who is here today, because we all share a common interest, obviously. There is a lot that can and should be said, and I am sure will be said. There will be expert testimony taken today, but there is another perspective that I don't know if anyone is going to address. I would like to just spend a minute or two now to focus on it, because I have a very real frustration. I think it is an emphasis that we have to-- I think we have to join together to see what we can do about this.

The FDA: There was a movement in the FDA earlier this year by Senator Kassebaum to make some changes to dramatically open up the door to speeding up the process of getting rid of some of the unnecessary prohibitions. All that does is-- It means that people's lives are at risk. People are dying because they cannot get the information they need. Oncologists-- There is no way that an oncologist can read every journal article on every

subject about cancer. It is a physical impossibility. But if the manufacturers -- like they used to do years ago-- They used to have continuing medical education seminars. Well now, the FDA says, "You can no longer do that, unless it is for an approved process, an approved label." If it is what they call "off label," they cannot share that information. They have to go through the whole regulatory process from start to finish again.

In 1993, it was estimated that it takes \$359 million to get a new drug to market. Now, this is horrendous. The Europeans have a system that we really have to take a closer look at, because the Europeans get competition in there. They have their government license agencies or groups that go through the certifying process, such as our FDA does now, and they work in competition, so they work in a timely manner. But they are subject to lawsuits for any liability. So that is your check and your balance. The system is speeded up and, therefore, the costs are lowered. The costs that the pharmaceutical companies have to expend to develop these drugs, that all gets passed on to us. We pay for it. It is a horrendous cost, but, more important than the cost, are the lives and the human suffering.

I would really like to see, in the future -- and I really want to focus on this very strongly in days to come-- We really have to make a united front through, whether it is the Cancer Society, whether it is other legislators in other states, really make a push nationwide to get things changed at the FDA, so that the FDA at least allows pharmaceutical companies to tell doctors what they have learned about the drugs that have been approved, but maybe not approved for specific treatment. It is an abridgment of our First Amendment freedom of speech rights. I am just amazed that it has not been challenged.

In any case, I am going to stop. I could say a lot more, but I won't in the interest of time. I just want to say to you that any of you who want to work with me on this-- This, to me, is a really top priority. I am just frustrated that we can't, as a State, make a direct impact, but we will certainly try.

Thank you.

ASSEMBLYWOMAN HECK: Charlotte has made an excellent point, as far as we are concerned, because she is looking at an evaluation of a system that seems to be stuck. We know from the testimony we have heard before on AIDS and HIV victims that there are things going on in other countries, things being used in a very successful way. I think a reexamination of the entire FDA process and the movement of that can be made. Perhaps we should hold another joint meeting and just focus on that particular issue, because it is a big one, and it is an important one.

We certainly know where we are today as far as cancer is concerned. People have asked us, "Isn't there a cure yet?" The radio stations have said to me, "How many cures for which kinds of cancer have been found?" Well, we are going to have experts address those subjects today. Maybe we are going to shake the tree a little bit today, Charlotte. I know that is why all of our Committee members want to do this type of a hearing, because it does help. It just doesn't help statistically. It helps individual people. We are going to find a number of victims here today who will speak from their hearts and will tell us what they need and what they want.

It is my pleasure to introduce to you the CEO of the Bergen Pines County Hospital, Ed Louis.

Ed?

EDWARD LOUIS: Good afternoon. On behalf of the Bergen Pines County Hospital--

HEARING REPORTER: Madam Chairwoman--

ASSEMBLYWOMAN HECK: Ed, you have to speak into the microphone. They are recording you. This is for posterity, Edward.

MR. LOUIS: Oh, I'm sorry.

Good afternoon. On behalf of the Bergen Pines County Hospital, I would like to welcome all of our guests and the members of the Assembly Policy and Regulatory Oversight Committee and the members of the Assembly Health Committee, and thank them for allowing Bergen Pines to host today's hearing on this very important subject in health care, breast cancer.

I do not want to take up time, because a lot of people want to testify. So, once again, thank you, and welcome.

ASSEMBLYWOMAN HECK: Thank you so much, Ed.

I would like to introduce to you the Chief Operating Officer here at Bergen Pines, Joan Wright, who herself is a former legislator. She has done an outstanding job for us as women.

Maybe you can touch on the health initiative that we came to the other day. But thank you very much, Joan, for being here and hosting this hearing.

JOAN M. WRIGHT: Well, I guess maybe I will have to sit, although I wanted to--

ASSEMBLYWOMAN HECK: No, no, why don't you just turn it around (referring to microphone).

MS. WRIGHT: I wanted to direct my comments to the public as well, but they will understand.

First of all, thank you very much to the members of the Legislature for choosing Bergen Pines County Hospital for this important public hearing. Breast cancer is, indeed, a public health issue, and we are very pleased that you chose to be here, in what is the only public hospital of its kind in the State, with psychiatric, long-term care, and acute services on one campus, 68 acres serving the public for 80 years. We are celebrating our 80th anniversary. We invite you, Sunday, October 27, to an open house here. There are flyers that I hope you will take as you go out.

We want to open this hospital up to the community so that people will know the kinds of services that are available to them here. One of the services available here that we are just so proud of happens to be mammography. I want to just introduce -- if you would stand so people can see you -- Bill Toeppe, Department Manager for Diagnostic Imaging, Irene Baus, Senior X-ray Lead Mammography Technician, and Dr. Bruce Javers, from UMDNJ, who leads our radiology team.

Thank you for being here today.

Also as you go out, there are all kinds of other flyers from the Bergen County Department of Health and from the YWCA.

When we are talking about breast cancer, we are talking about real people. I just want to recognize that Anne Wennhold, herself a cancer survivor, is here with us today, and how important it is that you have made your experience public through art and through speaking. Anne's exhibit, her mural of her experience, is on display now at the Art Center of Northern New

Jersey in New Milford, and on Friday, Anne will be speaking at the YWCA in Ridgewood as well, and there is a flyer on that.

Thank you for being here and for your outstanding work in bringing this to everyone.

The importance of enlightened women and men in positions of power -- the positions that all of you are in -- the ability that you have to affect change, making decisions regarding people's real lives-- I think that with cancer and with some of the other issues that are important to the public today, women especially, who always thought they were outside of the political process, are finally making the connection between what happens in Trenton and Washington and the impact on their lives. Sometimes it is not easy for women to take time away from their work or their home to speak out, where mostly we are not represented by paid lobbyists. Most of what you hear about women's lives you hear from women's hearts.

So thank you for being here. Thank you to all of you who are speaking out for yourselves and on behalf of other women as well. Never before -- I don't think ever before -- have there been so many things, both in Washington and Trenton, that affect the lives of women and their families who are finally coming forward to be heard in numbers greater than before. I am so thankful that we have enlightened legislators in Trenton who are hearing us and who are willing to do something about it.

Bergen Pines County Hospital is also pleased to be the site of the Women's Health Initiative. We are doing this as an off-center site with the New Jersey Medical School, University of Medicine and Dentistry of New Jersey. The Women's Health Initiative-- Here again, it was because the

National Institutes of Health and Enlightened Leadership, Bernadette Healy, that Congress appropriated \$628 million to the study of women's health, ages 16 to 79. The first time ever in this nation that women's health has been studied, and the largest health study ever nationally.

Bergen Pines is pleased to be a site for this study. We will be ready to open up in the next week or so with the New Jersey Medical School, which will be staffing it. Bergen County and the region have 85,000 women in this age cohort, and we are pleased that they will be coming here and that they may choose us for quality care as well.

The Bergen County Department of Health, represented here today by Pat Hegadorn, has received a grant from the New Jersey Department of Health for the screening of uninsured and underinsured women for breast and cervical cancer. Bergen Pines is pleased to be your partner, as are the five other hospitals in Bergen County. The goals of the grant are to regularly target women over the age of 56, and minority women who usually do not get identified, or do not feel comfortable coming forward. The grant will cover the costs of mammography and cervical screening at Medicare reimbursement rates, and all hospitals in the county, as I have said, have agreed to participate.

We are pleased as well to be part of the Bergen County Department of Health's Community Health Partnership, in which all hospitals and all public health entities in the county are doing a survey of present and emerging needs, so that together we can design, for the future, a Bergen County health system that will meet the needs of all. By all we do not just mean SAM -- standard American male. We mean all of us.

Welcome, and thank you for speaking out.

ASSEMBLYWOMAN HECK: Thank you very much, Joan.

First, we are going to have a presentation by one of the Summit sponsors: Dr. Paul Wallner, the Summit Chairperson, Director of Radiation Oncology, Cooper Hospital/University Medical Center, Professor of Radiology, UMDNJ, Robert Wood Johnson Medical School, Camden.

Doctor?

PAUL E. WALLNER, D.O.: Thank you very much.

I am honored to have been asked this afternoon to lead off the discussion for the sponsors of the Breast Cancer Summit meeting. I want to thank Assemblywoman Heck, Assemblywoman Vandervalk, and the members of the Assembly Policy and Regulatory Oversight Committee and the Assembly Health Committee for their support of this entire process. I also feel it is incumbent upon me to thank Governor Whitman and Mr. Whitman for their absolute, unequivocal support from day one in this process.

In late 1994, a number of us involved in the five groups which will be speaking to you in a few moments, sat together to discuss what we felt was a tragic and unacceptable situation: the fact that New Jersey has one of the highest per capita incomes in the United States, one of the highest densities of universities and health care delivery systems in the United States, but the third highest mortality rate from breast cancer in the United States.

In 1996, almost 2000 women in this State will die of breast cancer. That does not include the number of women who are living with breast cancer and the number of women who obviously will develop breast cancer in the near and long term. This was unacceptable, and it is unacceptable.

It was the determination of the five organizations -- the American Cancer Society, New Jersey Division, the New Jersey Commission on Cancer Research, the New Jersey Department of Health, The Cancer Institute of New Jersey, and The Medical Society of New Jersey -- that the only way to address this problem appropriately was to develop a summit where all interested individuals could convene to develop an action plan to try to deal with this issue. This was not a summit where individuals sat and pointed fingers at someone else, and said, "This is what we think you should be doing." This was an organization that convened to develop a plan as to what we should all be doing and what we should be doing better. In some instances, as you will hear in a few moments, this involves you, as legislators, and you, as public citizens.

We also want to thank some of the major corporations in New Jersey which helped us to get this Summit going. Ultimately, the Summit was held in May 1995 with over 125 organizations and individuals participating and represented. The purpose of the Summit was to develop a comprehensive action plan to reduce New Jersey's high-mortality rate from breast cancer.

The Summit was divided into four specific areas of thrust: early detection of breast cancer, treatment of breast cancer, research into cause, prevention, and treatment of breast cancer, and areas of health care policy. Across all of these areas fell the issue of data, data management, and data access, which we will deal with as a separate area this afternoon, but clearly relates to every other function. Without the appropriate information, we cannot make the appropriate decisions.

The report -- which you have -- represents a consensus of the participants of the Summit. We recognize that this is not an absolutely,

unequivocally, all-inclusive report. There is no way that a manageable document would have included every potential school of thought, every possible project, every possible idea. We attempted, from day one, to make this a pragmatic approach: What could we accomplish? It is absolutely useless and cruel for me to tell a woman with breast cancer today, “We may be able to help you in 20 years.” We need change today. This report was an attempt to deal with change today and in the near future.

I would like to beg your indulgence for a moment to read the final summary paragraph of the Executive Summary of the report, because I think that states, very clearly and concisely, why we are here this afternoon and what we will ask of you:

“A number of goals, objectives, and action items have been identified in this report. The success of the effort will rest on the willingness of individuals and organizations to take responsibility for designing and implementing energetic efforts to accomplish the goals. Most important is the need for the creative and dynamic collaboration of citizens, government, and private organizations in the State. The sponsors of the Breast Cancer Summit urge you to seek opportunities to participate in this important work. They look forward to the opportunity of working with all of the individuals and organizations committed to the reduction of mortality from this disease.”

In a few moments, you will be hearing from some of my colleagues in the Planning Group of the Breast Cancer Summit, and then I will ask your indulgence to finish up, for a minute or two, to point out to you some opportunities we think you may have in helping us.

Thank you very much.

ASSEMBLYWOMAN HECK: Thank you.

ASSEMBLYWOMAN WRIGHT: Rose, may I ask a question?

ASSEMBLYWOMAN HECK: Did you want to ask it now or after his group comes up?

ASSEMBLYWOMAN WRIGHT: It is just a technical question.

ASSEMBLYWOMAN HECK: Oh, okay. I think they will hear you. I think one is a mike and one is the recording mike.

ASSEMBLYWOMAN WRIGHT: Okay.

Thank you, Dr. Wallner.

ASSEMBLYWOMAN HECK: Assemblywoman Wright wishes to--

ASSEMBLYWOMAN WRIGHT: Mine is just a technical question: We received a chart on cancer mortality, 1993 deaths. Somewhere I saw a chart that said-- Maybe actually the Chairman can answer this question.

The chart we have in the back of the packet of materials, it has New Jersey listed as fourth from 1988 to 1991. Are you saying that more recently we have become third, that this is old data?

DR. WALLNER: That is correct. One of the problems in the data is keeping it timely. With more and more computer access, we hope to be able to do that. You must also understand that some of the patients who were diagnosed in New Jersey are treated ultimately in New York and Pennsylvania, and we are, to some degree, dependent on data from those states in timely reports.

ASSEMBLYWOMAN HECK: I think what is wonderful about the Summit is that they are bringing it all together and helping us to understand. That is why we appreciate all that you have done through this group. It is a cooperative effort, as you have said.

Do you want to introduce who is next, Doctor?

DR. WALLNER: I will be happy to do that.

For the discussion of early detection and health policy, I would like to introduce Ms. Donna Bocco, who is Director of Advocacy for the American Cancer Society, New Jersey Division, and Dr. Jeffrey Wenger, who is the Chairperson of the Breast Health Task Force of the American Cancer Society, New Jersey Division.

J E F F R E Y W E N G E R, M.D.: Thank you, Dr. Wallner, and thank you, Madam Chairwomen and Assembly members for the opportunity to speak to you today on behalf of the American Cancer Society, New Jersey Division, a principal sponsor of the Breast Cancer Summit.

Several facts came to light during the Breast Cancer Summit which are of particular concern to us. The incidence of breast cancer in New Jersey is rising and the percentage of early stage cancer is less than the national average. The American College of Surgeons reported that, on the whole, poor women, older women, and African-American women have their breast cancer diagnosed at later, less curable stages. HCFA has shown that women in New Jersey greater than 65 years old have the second lowest utilization rates of mammography in the country. The Hospital Research and Education Trust has shown that utilization of mammography varies throughout the State, and

they also report that while the national average cost of a mammogram is \$90, the average cost of a mammogram in New Jersey is \$135.

Because of the national trend showing that tumors are being diagnosed at smaller and more curable stages largely because of a dramatic increase in utilization of mammography, and because mammography is the only proven technique to detect breast cancer that could lead to a decrease in mortality, the American Cancer Society feels that mammography must be made available to all women.

The Breast Cancer Summit has chosen, as a major objective, the reduction of the average size of tumors and diagnosis to two centimeters or less by early detection. The action steps to accomplish this have been outlined in our report, with which you are already familiar. These goals include: Education of all groups of women about the importance of early detection; a 20 percent increase to a level of 50 percent in the participation of women 65 years and older participating in regular mammography program screening -- currently, HCFA shows that only 31 percent of these women are participating in regular mammography screening; the provision of culturally sensitive outreach programs to minority and socioeconomically deprived women; the development and implementation of an educational program for physicians to increase referral for mammography to 85 percent. A disturbing 1994 American Cancer Society, New Jersey, survey showed that only 40 percent of women who saw their physicians that year were told to undergo a mammogram. We must focus our resources in target regions of the State based on demographics, stage of diagnosis, and incidence of breast cancer, so that

screening can be increased to a level of 60 percent of women greater than 40 years old.

We must encourage employers of the State to initiate or expand work site screening and educational programs. Women should be surveyed randomly regarding their attitudes and concerns about mammography, as well as their intentions to return for follow-up or annual screening.

There are 19 steps in the report which have been outlined, and I urge you and your Committee members to review these specifying how we will attempt to accomplish these goals.

In summary, we must overcome all barriers to full access to women for mammography, whether they be economic, socioeconomic, sociocultural, or educational.

D O N N A B O C C O: Good afternoon. Thank you for the opportunity to address you today.

As one of my key duties as Director of Advocacy for the New Jersey Division of the American Cancer Society, I staff the Breast Health Task Force, a group of medical and allied health professionals and interested laypersons who are committed to responding to issues surrounding the early detection of breast cancer and supporting the programs in our local units around the State. Other volunteers and staff work to provide services to women who are undergoing a bout of breast cancer, which includes information and referral regarding treatment options and rehabilitation issues. Others raise money to support research. The Society, last year, dedicated \$13.4 million to breast cancer research alone.

I am sure it is apparent as to why we collaborated with the four other sponsors to work on the Summit which is the basis of this afternoon's hearing. All of our agencies have pledged leadership in specific areas of this plan to avoid duplication and the wasting of diminishing resources.

It is critical to understand that while the research is being conducted and answers to major questions are beginning to be forthcoming -- and becoming better understood, I might add -- we must continue to make sure that women go for mammograms at approved centers at appropriate intervals.

We are working in collaboration with interested agencies to make sure that there are no forgotten women. We work with the State Department of Health and Senior Services to increase consistent and good mammography services to minority women, non-English-speaking women, and older women. We have committed relationships for specific programming with the National Council of Negro Women and the National Association for the Advancement of Colored People. We are beginning inroads into Asian and East India populations and, consistent with these approaches, we host and are a working member of the State's Breast and Cervical Cancer Control Initiative.

What we are asking -- and the other sponsors, I am sure, will have other specific requests -- is that you lend your very concerned voices as leadership legislators in health and oversight to the broadest use of limited resources, to nonduplicative activities, to relieving some of the burden on the Department of Health and Senior Services whereby other organizations may be able to deliver some community outreach programs, to encourage the use and inclusion of those organizations considered authorities because they are

made up of learned professionals and respected laypersons, people who have undergone bouts of breast cancer, and other representative of our special communities.

Time does not permit going into details, but the American Cancer Society will work to get its Tell-A-Friend Program into our targeted communities. This is a packaged, scripted program which encourages women who have had a mammogram to partner with another woman and get her to commit to getting a mammogram, and the follow-up mammograms, age appropriately. We would like your help in transporting our special populations to mammography centers in a State that is “public transportation compromised.”

ASSEMBLYWOMAN HECK: Not for long.

MS. BOCCO: Good.

We will conduct a physician and medical office training program to underline the role of physician recommended mammography.

In issues surrounding health policies, provisions in insurance and managed care covering the early detection/treatment options and rehabilitation, we need your help, we need your vigilance, and we need your oversight.

In issues of employment discrimination based on genetic history or a past bout of breast cancer, we need your help, your vigilance, your guidance.

In the collection of reportage and data in order to capture this problem and really address it in the best possible manner, we need your help in the wise expenditure of the limited funds.

We will continue our joint effort in an October Breast Cancer Detection Awareness Project with hospitals and mammography centers statewide. This demonstration/education program offers a woman instruction in breast self-examination, a clinical breast examination, and a \$40 mammogram. To date, we have reached over 35,000 women. Not enough.

We offer the use of our 1-800 number, 1-800-ACS-2345 for information and service, not only for what the American Cancer Society offers, but all of the other people committed in the State of New Jersey.

In closing, you have the promise of the American Cancer Society that we will continue to deliver in all areas of the action plan -- because, as you know, we support research, and a host of other things -- leadership in the early detection portion, and we invite all interested parties in the State to join us.

Thank you for your support.

ASSEMBLYWOMAN HECK: Thank you, Donna.

I just want to mention that Donna is a super person to have on your committee, because I see her everywhere fighting the good fight. The Tell-A-Friend Program is so very important.

Assemblyman Jones has a question.

ASSEMBLYMAN JONES: Thank you.

Just for the gentleman: You mentioned that there is a stark difference in the cost from a national average standpoint for mammogram testing. I think you said the national average was approximately \$90 for a mammogram, and in New Jersey, the cost is approximately \$135.

You know, when we begin to look at the differences that seem to occur between racial and ethnic groups and recognize that African-American

women with breast cancer are less likely to survive a five-year period, and a white -- Caucasian woman, and the disparity, obviously, you know, in that cost data, somehow it works its way back not just regionally, but from a socioeconomic standpoint.

My question is: Why would there be that difference, you know, almost \$45 between the national average cost and our statewide average cost for a mammogram, you know, just on the preventative side?

DR. WENGER: I would suspect that some of it may simply have to do with the higher cost of living in the State of New Jersey. I saw a recent survey looking at what it costs to go to the dentist in the State of New Jersey and what it costs to have a routine dental visit in Idaho. It was three times higher in New Jersey than in Idaho, so I suspect that some of it may have to do with the cost of living.

ASSEMBLYWOMAN HECK: The cost is coming down, though. When we first started, it was over \$300. Was that being overcharged?

DR. WENGER: Yes. It has come down considerably, but we still, I think, have a way to go.

ASSEMBLYMAN JONES: When you say "a way to go," you mean in terms of bringing costs down. We are making it more affordable for those, obviously, who are less fortunate, you know, those who it has been too expensive for. I would assume that if folks are not able to afford a mammogram for reasons of out-of-pocket costs, just for the sheer lack of adequate health care, then that is obviously going to add to the mortality table, particularly with respect to African-American women and women who are, perhaps, in a certain socioeconomic bracket.

DR. WENGER: That is why it is so important that we continue and expand programs like the Breast Cancer Detection Awareness Project, where women can have a mammogram for \$40.

MS. BOCCO: Also, the no-cost mammography you will hear more for women who are uninsured, underinsured, or who have economic problems. When you hear from the New Jersey Department of Health, which will be testifying in just a few short moments, you will get further information in that regard.

ASSEMBLYMAN JONES: Thank you.

ASSEMBLYWOMAN VANDERVALK: I would also like to address your point, which is very well taken, but a lot of hospitals, and even some of the private clinics, will specify a certain period of time where they will have screening programs, and the cost comes down dramatically. Bergen Pines has an ongoing screening program where the cost is \$50, and has been for a number of years. So that is a substantial difference.

I recognize that it is still \$50, but I think that within the program we have at the Pines, there are exceptions for low-income people and people who really still need help beyond the \$50 level.

ASSEMBLYMAN JONES: I think that is good to know. I certainly think that is a good first step. You know, the Assemblywoman started out her comments indicating that in our county alone, you know, 4200 cases of breast cancer between 1985 and 1991, leading to 148 deaths. Essex County has a segment of its population which is below a certain income level. That no-cost feature, I think perhaps, even makes more sense than you know \$50, given the sensitivity of the issue.

ASSEMBLYWOMAN HECK: Just as a point of information -- and I am sorry I don't have the name of the hospital here -- there is an Essex County hospital -- I gave the information to Shirley Chatham -- where mammographies are done free through a grant process in Essex. So if you will just remind me, I will tell my staffers to give you that name.

ASSEMBLYMAN JONES: I would appreciate that.

ASSEMBLYWOMAN HECK: But Shirley has it, too.

ASSEMBLYMAN JONES: Okay.

DR. WALLNER: If I may make one comment regarding that: One of the things we have seen is that the highest density of mammographic facilities tends to be in the areas of lowest density population.

ASSEMBLYWOMAN HECK: Dr. Wallner, that is not an amplifying microphone. Apparently, the microphones are not picking up properly. I am going to ask all of the Assemblypeople and the presenters to please speak in your stage voices, your mother or father, brother or sister voices, so they will carry.

Assemblyman Pascrell has joined us. I just want to recognize him.
Yes, Assemblywoman Wright?

ASSEMBLYWOMAN WRIGHT: Can we just talk for a minute about Dr. Wenger's comment. Maybe I didn't hear all of what you said. Did I hear you say that 40 percent of the physicians referred their patients? Can you talk about that? What is going on there? Are you saying that 60 percent of women who went to physicians did not get referred?

DR. WENGER: When asked in a survey whether women went to their physician or not -- it was a two-part survey-- "Did you go to a physician

within the last year?” Of those who did, they were then asked, “Did the physician recommend a mammogram?”

ASSEMBLYWOMAN WRIGHT: And 60 percent did not.

DR. WENGER: That is correct.

ASSEMBLYWOMAN WRIGHT: So that obviously has to be a big part of what we are going to do. It has nothing to do with the Legislature, but with the practice of medicine.

DR. WENGER: Right, that is why part of one of our action plans is to provide programs of education for-- We are always talking about educating the public. Physicians need to be educated significantly also.

ASSEMBLYWOMAN WRIGHT: Your mike may not be turned on out there, the silver mike.

MS. BOCCO: It's on.

ASSEMBLYWOMAN WRIGHT: Now it's on.

ASSEMBLYWOMAN HECK: Dr. Wallner, I am going to ask if two people can be taken out of the list. Could you sit there, because I think it is important to you, too?

Assemblywoman Weinberg has a question.

ASSEMBLYWOMAN WEINBERG: Yes.

Along with Assemblywoman Wright, I was a participant in the Breast Cancer Summit, which I just want to remind everybody was held almost 18 months ago. Your report came out almost 6 months ago. So we are already halfway into some of the things that you wanted to get done in your action plan. We are already halfway into the period of time which was laid out in that action plan.

I have a few questions. I don't know how much of it you are on the road to accomplishing, whether or not there has been a conclave of some of the people involved so that some of the action plan that is not necessarily legislatively oriented, like, for instance, increasing the number of new hospitals that have an approved cancer program -- we talked about the fact that only a very, very small percentage of hospitals in New Jersey have an approved cancer program -- whether or not anything has been done along those lines, whether that road has been traveled at all.

DR. WALLNER: I do not want you to believe that nothing has happened between the publication of the report and this afternoon. The sponsors have been meeting continuously to divide responsibilities, and all have signed on to specific areas of responsibility, including that issue. So there has been progress and movement in all of those areas.

ASSEMBLYWOMAN WEINBERG: Will we be privy to the kinds of responsibilities that have been assigned? I think it would be very helpful to the members of this Committee if we could kind of monitor, or be involved in what that process is.

DR. WALLNER: Well, for practical purposes-- At its simplest level for practical purposes, each of the presenters this afternoon, at least for the Summit group, is representing the areas of their responsibilities. So the representatives of The Cancer Institute of New Jersey and the New Jersey Commission on Cancer Research will discuss issues of therapeutics and research, which are areas that they have assumed as primary expeditors, if you will. The American Cancer Society is the primary expeditor for the areas of early detection and health care policy, and the New Jersey Department of

Health for the early detection and data collection portions. That is the way, in essence, for the five principal organizations. The primary issues have been divided so there would be a leadership role in each of those five areas.

ASSEMBLYWOMAN WEINBERG: I think it is important for us, as well as for the public, to know the kind of progress that is being made.

I have a lot of feelings about the data collection, which I know is the province of the Department of Health. That has been one of my pet projects for almost four years. Finally, after going through one and a half Commissioners of Health, we finally got some money and some of the answers to the fact that we don't really know what is happening with breast cancer in the State of New Jersey, because our--

ASSEMBLYWOMAN HECK: May I respectfully interrupt you, because we have two people who are vitally important to this hearing who have to leave by 2:30. I will give you the floor again to speak to Dr. Wallner as we wrap up.

ASSEMBLYWOMAN WEINBERG: Well, all right.

ASSEMBLYWOMAN HECK: I want to get information coming to us from a lot of different people. This is kind of a wrap-up, and you can wrap it up with that later.

ASSEMBLYWOMAN WEINBERG: Okay, thank you. I certainly will.

Again, I would like to say that we don't really know what is happening with breast cancer in the State of New Jersey, because our cancer registry is so far out of date.

ASSEMBLYWOMAN HECK: That is why we are having this hearing.

ASSEMBLYWOMAN WEINBERG: We finally got some funds, very recently, and when the Department of Health comes up I will comment on that. But I wanted to make that point.

ASSEMBLYWOMAN HECK: We have a report coming from them, Assemblywoman. You are a little premature.

ASSEMBLYWOMAN WEINBERG: No, I think I am about four years too late.

ASSEMBLYWOMAN HECK: Dr. Wallner, I am going to ask Dr. Jeanne Beck and Sharon Bates to come up, please. Dr. Jeanne Beck is from Coriell Institute, a member of the New Jersey Advisory Group on Breast Cancer Research.

We have a lot of wonderful people here who will give us information. We are trying to glean how much has been done, how much needs to be done, and what we can do, as a Joint Committee. I think I want to concentrate on what we can do in a positive way, and not look to the years of service that each of us has given in different areas.

Dr. Beck? And, Sharon, would you please come forward to save me some time, because I know you have to leave in a short time, too? Sharon is a survivor.

JEANNE C. BECK, Ph.D.: Good afternoon, ladies and gentlemen. I am Jeanne Beck, an Associate Professor at the Coriell Institute for Medical Research located in Camden, New Jersey. I am a scientist whose basic research activities include breast cancer research. I am currently a member of the Breast

Cancer Advisory Panel of the New Jersey Commission on Cancer Research and a member of the Biological Specimens Working Group of the National Action Plan on Breast Cancer.

I am grateful for the opportunity to appear before you today to provide input regarding implementation of the Breast Cancer Summit recommendations as outlined in the formal report. The action plan addresses several areas, including early detection, therapeutics, health care policy, and research. I am here today to comment on the Action Plan for Research.

The report concludes that, “An active and dynamic basic, clinical, epidemiologic, and psychosocial research strategy is critical to the reduction of the mortality from breast cancer.” Further, the report sets as some of its goals increasing New Jersey’s share of Federal research dollars and enhancing collaborations between basic researchers and clinicians.

In my opinion, thanks to the Legislature, and specifically to Assemblywoman Heck, a critical barrier which has limited participation in research studies has been removed. With the Genetic Privacy Act, we will now have in place the protective legal infrastructure to encourage individuals to be part of research studies and research protocols.

Furthermore, the State has taken a proactive stance with regard to broad public education about breast cancer research. While the checkoff on line 55 of our 1996 income tax return will raise funds for breast cancer research, we should not underestimate the effect it will have on public awareness. The Legislature deserves great praise for taking that step.

Given the conclusions of the action plan, how can we develop an active and dynamic basic research strategy? We at the Coriell Cell Repositories

would argue that research resources, such as biological specimens, coupled to epidemiologic data, family history information, and outcomes data, provide invaluable materials to investigators for breast cancer research.

You are all aware that the Coriell Institute houses a collection of cells from a variety of diseases for use in research. If we look for a moment at the information which has come out of this collection of cells at Coriell, we can appreciate the importance of research resources, such as cell banks. Numerous genes have been identified in materials provided to the research community by the Coriell Cell Repositories. These include the genes for Huntington disease, Alzheimer disease, manic-depressive illness, and retinitis pigmentosa, among many others.

We at Coriell have recognized that there is a shortage of raw materials for breast cancer research. In fact, we have been asked repeatedly to provide such specimens. Those scientists who do research in clinical settings have little or no problem gaining access to patient biomaterials for research. Others in the many laboratories outside of a clinical setting find it difficult or impossible to obtain high-quality human materials for analysis. Through a seed grant from the New Jersey Commission on Cancer Research, in collaboration with Dr. Ravikumar at The Cancer Institute of New Jersey, the Coriell Cell Repositories have been funded to set up a repository of biomaterials for cancer research. This repository, which contains biological materials from patients with a variety of cancers, will be a critical resource for scientists in New Jersey. But we must do more to create and extend support for the kind of resource that will enable New Jersey scientists to move more

rapidly and to create the kind of advantageous environment that will attract funding to this State.

I would urge the Legislature to support the establishment of centralized shared resources, such as cell banks and data banks. Such resources are truly catalytic. Because each individual does not have to spend time in the redundant collection of numerous materials or data, science will move more quickly. I would also argue that this kind of an investment will move us further toward reaching some of the goals set by the action plan. These resources will foster collaborations within the scientific community and ultimately increase New Jersey's share of Federal research dollars.

Thank you very much for your attention.

ASSEMBLYWOMAN HECK: Thank you very much for coming, Jeanne. I know how busy your schedule is, but this is the important data we need. We want suggestions that we can do something about.

Does anyone have a question for Dr. Beck? (no response)

Thank you very much.

Sharon Bates, who has to go, I think, to work. Really, it is very important for her to be here.

S H A R O N B A T E S: Good afternoon, and thank you for allowing me to speak to you.

My name is Sharon Bates, and I was diagnosed with Stage 3 breast cancer on April 18, 1989, on my birthday. Since that time, I have had eight to nine operations and, due to that, on my job, right now, I have charges brought against me to be dismissed because of the absenteeism.

After, I don't know which operation, I developed fibromyology. It is almost like arthritis. I never know when I am going to be able to sit up, stand up, or turn over in bed. I take approximately eight to ten pills a day.

Last year, we got a new building principal, and I became his target. Since that time, I have had four schedule changes. I was put in the subbasement where I had to walk up the stairs. I asked for a transfer at the end of last year. I was not told that it was denied, or anything. On September 3, my principal called me into his office at 2:30 in the afternoon and gave me legal papers saying that he was bringing charges against me to have me dismissed. So right now, I am in the process of going through that legal problem.

This has not only affected me, but it has affected my family. I am a single parent with three children. Dealing with the breast cancer is enough. I do not need this added aggravation.

My doctor, Dr. Santora, told me to get in touch with Assemblywoman Heck's office because she is concerned about the weight I lost and my health in general. Actually, all my doctors are concerned. This has become a real problem. This is not only for myself. I do not want to see any woman go through what I have had to. My Assemblyman, Mr. Pascrell, knows me well and knows that I have been involved in the community for over 17 years. With my health, although I have been out approximately three months at a time due to my health, I never know what is going to happen. I mean, I get up in the morning and I don't know if I am going to be able to sit up or stand up.

My children have had to sit me up, turn me over. A couple of weeks ago, I had an incident that lasted approximately two or three weeks, where the lower part of my body was shutting down. My doctor said to me, "Why didn't you come into the hospital?" Due to the fact that it affects my household, my kids, I try not to go to the hospital unless it is an extreme emergency. I ended up in the emergency room due to the stress of dealing with the legal problems about my absenteeism due to my breast cancer.

Right now, I don't know what is going to happen. I really and truly don't know what is going to happen.

ASSEMBLYWOMAN HECK: So what you are looking for, and what you are telling us is that besides the physical problems you have, the cancer that you have suffered, you are also suffering from a kind of a job situation.

MS. BATES: Right.

ASSEMBLYWOMAN HECK: So you want protection for not only you, but for other people who are in similar circumstances, and you are bringing this out. This is shocking.

MS. BATES: Basically, I was harassed last year for surviving.

ASSEMBLYWOMAN HECK: For surviving.

MS. BATES: For surviving.

ASSEMBLYWOMAN VANDERVALK: May I ask you: Did you say you were a teacher?

MS. BATES: Yes.

ASSEMBLYWOMAN HECK: Are there any questions you may want to ask Ms. Bates?

ASSEMBLYWOMAN FRISCIA: Sharon, where do you teach?

MS. BATES: In the Paterson public school.

ASSEMBLYWOMAN FRISCIA: Paterson? I would like to talk to you.

ASSEMBLYMAN FELICE: May I ask a question, Madam Chairman?

ASSEMBLYWOMAN HECK: Go right ahead.

ASSEMBLYMAN FELICE: The problems you are enduring, are they due to the medication you are taking, or are they from the cancer-related problems you had?

MS. BATES: They are probably due to-- After chemo, I developed-- I did not have the problem with my back. After one of the operations, I started having back pain, spasms in the back. I have been hospitalized. I have been in and out physical therapy. I have been in pain management. I have been in every kind of program you can imagine for my back. I have had chiropractic treatments. I never know when it is going to happen. I can go to bed feeling fine, and wake up in the middle of the night and not be able to turn my body over, or I can go to bed and wake up the next morning and not be able to get up, or it takes me a long period of time.

ASSEMBLYMAN FELICE: Having had, years ago, a member of my family go through chemo, and so forth, I am just wondering if you-- You are not taking chemo at this time, are you?

MS. BATES: I'm off the chemo right now.

ASSEMBLYMAN FELICE: And you're taking medication?

MS. BATES: I am taking medication. I have been on percocet, datrol. I have had some of the strongest pain medicine that they can give me. Nothing has really helped. I am never completely out of pain. I have been told to take the medication at the onset of the pain so it doesn't get out of control.

ASSEMBLYMAN FELICE: You might take medication when you are at work even, when necessary?

MS. BATES: Yes, I have to.

ASSEMBLYMAN FELICE: Thank you.

ASSEMBLYWOMAN HECK: Assemblyman Pascrell?

ASSEMBLYMAN PASCARELL: Hi, Sharon.

MS. BATES: Hi.

ASSEMBLYMAN PASCARELL: Madam Chairlady, I want you to know that I have known Sharon for many moons. She has taught for 17 years.

I have a question, if I may, through the Chair, to ask of Sharon.

ASSEMBLYWOMAN HECK: Certainly.

ASSEMBLYMAN PASCARELL: I don't know of the specific situation -- I am sure we don't want to get into that here -- in terms of your employer, but just talking globally about it I am sure sensitizes everyone on the Committee -- on the Joint Committee. What do you think-- What direction -- I think you are a good example to answer the question, Sharon, if you would, not that you have to. What direction do you point to, or where should we be going with situations where one's job is either put on the line, or jeopardized, or where there is some lack of understanding about what this is all about?

I mean, how do you see closure in this kind of a situation, not only for yourself, but for others in the same situation?

MS. BATES: I don't think anyone should be forced out of her job due to-- I don't think anyone should be forced out of her job because she has breast cancer and, as a result of that, she develops complications, which have been documented. It is not like I have a headache and I am staying out of school.

Usually, when I have been out it has been, like, for a two-week period of time, or a longer period of time than that. Just to give you an example, I am one of these people who, when I catch a cold, it is not like if you catch a cold. Because of my immune system, a cold is almost dangerous for me because of the possibility of pneumonia. Last year, I did catch a cold. It lasted about two and a half weeks. I went back to work, against my doctor's wishes, due to the fact of what was going on in my building. I started going in a half day. The doctor said, "Well, go in for a half day and see how you feel."

Well, going in for a half day, that was used against me. I don't think illness should be used against anyone in this situation.

ASSEMBLYWOMAN HECK: I think you need an advocate, Sharon. I really do. I think some of us would like to meet with you after this so we can address this.

Yes?

ASSEMBLYMAN PASCRELL: If I may continue?

ASSEMBLYWOMAN HECK: Go ahead.

ASSEMBLYMAN PASCRELL: Are you out of sick time?

MS. BATES: Well, this year I tried to go in because of the legal complications I am having. In the previous year, I used up my sick time. I think after 10 years you get additional days. I used that. I have been out on family leave at different times.

ASSEMBLYMAN PASCHELL: So, in other words -- through the Chair -- when you are out of sick time it means that you are not going to be paid.

MS. BATES: Right.

ASSEMBLYMAN PASCHELL: Is that correct? Has that happened to you during this process?

MS. BATES: Yes, that has happened.

ASSEMBLYMAN PASCHELL: So you have been out of work at times during the situation that--

MS. BATES: At times, for three months at a time.

ASSEMBLYMAN PASCHELL: During those periods of time, because you did not have any sick time left, did not have any extended sick time left, you did not get paid?

MS. BATES: No, I did not.

ASSEMBLYMAN PASCHELL: So you were home, in the situation which you have just described to us. What money was coming into the house?

MS. BATES: There was no money. My family literally had to take care of me.

ASSEMBLYMAN PASCHELL: Have you ever discussed with your employer a leave of absence? I am not recommending it, I just wondered.

MS. BATES: Not since I started back to work. I have not taken a leave, like, for a whole year.

ASSEMBLYMAN PASCHELL: But if you did take the leave, that would mean that you would not be getting paid either.

MS. BATES: No.

ASSEMBLYMAN PASCHELL: Your medical protection would continue, your coverage would continue, but you would not have any--

MS. BATES: Income.

ASSEMBLYMAN PASCHELL: There would be no income.

That is the point. We have discussed this with other people in similar situations, Madam Chair, and the question is, and I will go back, have we researched what the possibilities are, or do we have to go to the individual contract of each employer/employee to work out, or bring to closure this particular situation? I mean, this is something that is ongoing.

I can understand the employer wanting to have some permanent person teaching that class. I mean, we have to understand that as well. But I certainly can understand a young lady who has been certified to teach, has taught, has performed admirably. In this particular situation, what she is asking us, I think -- and correct me if I am wrong-- She is down the path of extended sick time. If she goes on leave, she doesn't get paid. What is she to do?

Well, the first thing is, you know, if she quits her job, then she has no coverage. Then she is in a worse situation. What does the district do? What does the employer do to help her? Is there a way out of this particular situation? I mean, I have a couple of alternatives, but I wanted to hear from--

ASSEMBLYWOMAN HECK: Sharon.

ASSEMBLYMAN PASCHELL: --from Sharon if she has any ideas of what she thinks would be a resolution to this.

Thank you, Madam Chairman.

MS. BATES: I have one more thing to say: I was an unassigned teacher, not directly in a classroom, for at least, I think, two or three years. I was a resource person where students from other classes would come into the computer room and I would help them. I was not assigned to a class until last year. So I was missing from a class on an everyday basis. I was an unassigned teacher. I had students from all over the building who would come in and work on the computers. I would work with them during the course of the day. It wasn't the same students every day. I just wanted to clear that up for the panel also.

The building principal before the principal we got last year worked with me -- worked on a schedule that was good for me and good for her and the school. I did a lot of things that compensated for my not having a full schedule within--

ASSEMBLYWOMAN HECK: You were working on flextime?

MS. BATES: Yes.

ASSEMBLYWOMAN HECK: That is one of the things that we look at as women -- flextime. What you are saying is that that worked out well with a particular person who understood your situation--

MS. BATES: Right.

ASSEMBLYWOMAN HECK: --but right now, no care is being given in that area.

MS. BATES: Last year, when I went in on the first day, I was told that my building principal was asking about me, had questions. In the process, I wrote a memo to him listing all the things I did during the course of a day, and requesting that if he needed to talk to me with reference to what I was doing-- He chose not to. Actually, he never spoke to me.

ASSEMBLYWOMAN HECK: I don't think we should think in terms of an individual, at this point. I think what you are looking for is a safety net, not just for you, but for others.

Dr. Wallner, have you heard of similar problems?

DR. WALLNER: Absolutely.

ASSEMBLYWOMAN HECK: Oh, you have? This is not an isolated incident.

DR. WALLNER: The American Cancer Society, New Jersey Division, actually has a committee which serves on an ongoing basis in an advocacy role for individuals and groups that have found this kind of job discrimination. It is a significant issue, and it is not to be reckoned with easily.

ASSEMBLYWOMAN HECK: Assemblyman Jones?

ASSEMBLYMAN JONES: Thank you, Madam Chair.

Through you, I just think that in this day and age, particularly with, you know, not just breast cancer, but the multitude of catastrophic illnesses individuals, both male and female, find themselves facing, that we do not yet have something just very fundamental, a health care policy which speaks clearly to job protection in instances like this.

You know, the Doctor mentioned that there was an advocacy group set up that basically oversees these issues of discrimination. But what

I would like to ask the Doctor is with respect to these summits that have been created. Have there been any specific recommendations that would hinge on a more statewide health care policy that would embrace this notion of job protection, given the testimony that Ms. Bates has given this Committee?

DR. WALLNER: Recommendations have been made on a regular basis. Unfortunately, there would be more representatives from the insurance industry sitting in this room than there are from the advocacy groups to dispute doing what you are suggesting.

ASSEMBLYMAN JONES: Through you, Madam Chair, to be quite honest, I could care less--

DR. WALLNER: Well, I am on your side.

ASSEMBLYMAN JONES: --about what those insurance companies think right now. What we are all concerned about are people like Ms. Bates.

ASSEMBLYWOMAN HECK: Protection.

ASSEMBLYMAN JONES: So what I would like to hear from you is -- if you can share them with us -- what those recommendations are, so that we have an idea of where we are going and how we get there. The insurance companies will have their day, but right now, this is Ms. Bates' day, and the countless others in this State who need to hear those things.

DR. WALLNER: Actually, on the list for my concluding remarks, that is exactly one of the things we are going to ask you to work with us on.

ASSEMBLYWOMAN HECK: Oh, good.

ASSEMBLYMAN JONES: So we did not get to that yet?

ASSEMBLYWOMAN HECK: No, no, we did not get to the conclusions yet.

ASSEMBLYMAN JONES: But, Madam Chair, one other thing that I would like to add before you get to Assemblywoman Friscia, is that I believe what is lacking, also, is the issue of public awareness. I think if more people are made aware of the issues of breast cancer and the ultimate results a breast cancer victim has to face on a day-to-day basis, particularly in Ms. Bates' situation, then that ultimately would lessen the problem and get us more quickly to embracing the recommendations we will hear later.

So I think the core issue, the fundamental issue, is also one of awareness, particularly among men. We do not quite understand. You know, I include myself in that category of men who do not understand the impact that breast cancer has on women. That is just a fundamental flaw in this society right now. I hope the recommendations we hear will serve to cure those flaws.

ASSEMBLYWOMAN HECK: We also have males in this category. We have a male survivor here to speak today, too.

ASSEMBLYMAN JONES: Yes, about 1400 in 1995.

ASSEMBLYWOMAN HECK: I think it is very important for all of us, both Committees, and that is why we are doing it jointly, because we do have similar goals, awareness being one of them. But other conclusions will be raised, as Assemblywoman Weinberg was looking for before, and that is right on target. We are going to do that as a Joint Committee.

Assemblywoman Friscia?

ASSEMBLYWOMAN FRISCIA: Sharon, you mentioned before that your principal handed you charges. How long ago was that?

MS. BATES: September of this year.

ASSEMBLYWOMAN FRISCIA: Have you had any hearings?

MS. BATES: Actually, I am going to a meeting at 3:30 this afternoon to discuss some information about it.

ASSEMBLYWOMAN FRISCIA: Not with the administration?

MS. BATES: No.

ASSEMBLYWOMAN FRISCIA: Okay. I would like to see you out in the hall, because I have some suggestions for you. Are you being represented by the NJEA?

MS. BATES: Yes.

ASSEMBLYWOMAN FRISCIA: Okay.

ASSEMBLYWOMAN HECK: Thank you very much.

MS. BATES: Thank you.

ASSEMBLYWOMAN HECK: Sharon, you will be hearing from a number of us, I am sure.

MS. BATES: Thank you.

ASSEMBLYWOMAN HECK: You can mention wherever you are going that you did speak with us today.

MS. BATES: Okay.

ASSEMBLYWOMAN HECK: You can tell whoever your building person is that you have spoken to us.

ASSEMBLYMAN JONES: Tell them that Assemblywoman Heck sent you.

ASSEMBLYWOMAN HECK: Dr. Wallner, two of your people on the major issues, therapeutics and research, are going to have to leave soon. Maybe you would like to take them out of order.

DR. WALLNER: Sure, okay.

The Cancer Institute of New Jersey and the New Jersey State Commission on Cancer Research have assumed the responsibilities for leadership roles in breast cancer therapeutics and research. In that regard, sitting on my right is Dr. David August, who is a member of The Cancer Institute of New Jersey and Associate Professor of Surgery at UMDNJ, Robert Wood Johnson Medical School. And to his right is Ann Marie Hill, who is the Executive Director of the New Jersey State Commission on Cancer Research.

DAVID AUGUST, M.D.: Good afternoon. My name is David August. I am from the University of Medicine and Dentistry of New Jersey, Robert Wood Johnson Medical School, and a member of one of the primary sponsors of the Breast Cancer Summit, The Cancer Institute of New Jersey. I come before you today wearing the hat of a member of The Cancer Institute of New Jersey and as a member of the Breast Cancer Advisory Group of the New Jersey Commission on Cancer Research.

The Commission on Cancer Research has been given the primary responsibility for the research issues addressed in the Breast Cancer Summit report. Similarly, The Cancer Institute of New Jersey has been given the primary responsibility to address the therapeutic issues in that report. In practice, these issues are so intertwined that we have chosen to work on these issues as partners. The relationship between therapeutics and research is

absolutely vital. The bottom line is that the best treatments we have to offer breast cancer patients right now simply are not good enough.

Women in the State of New Jersey continue to die from breast cancer. If we are going to improve on what is now the best we have to offer, basic research initiatives must be translated into concrete treatments and interventions to improve breast cancer patients' health. The goal of research, in part, is to improve therapeutics. This can happen efficiently and effectively only by coordination between therapeutics and basic research. Basic research advances must be translated into advances that improve and save women's lives.

An additional role for the relationship between research and therapeutics in our current changing health care environment is that it has become clear that generation and dissemination of general standards of care can play an important role in broadly improving the quality of treatment for large groups of women. In order to create and disseminate such standards in an irrefutable and persuasive manner, these standards must be created from the results of clinical research trials. Therefore, improved therapeutics on a population-wide basis are dependent upon effective, high-quality research data.

Ms. Ann Marie Hill, of the New Jersey Commission on Cancer Research, and I have chosen to highlight three issues to address with you today:

The first relates to the stability of funding for breast cancer research, both clinical and basic, within the State of New Jersey.

The second relates to improved collection, distribution, and dissemination of data concerning breast cancer, breast cancer treatment, and breast cancer research within the State of New Jersey.

Thirdly, we wish briefly to highlight the importance of the facilitation and support of clinical research trials within the State.

Before asking Ms. Hill to address the issue of stability of funding for breast cancer research, I just want to highlight the importance of undertaking these initiatives actually within the State of New Jersey, not relying on other entities, not relying on the Federal government, not relying on other states. By conducting high-quality research and having high-quality clinical programs within the State, breast cancer patients from within the State will have the most immediate access to state-of-the-art care from cutting edge researchers and clinicians. We cannot rely on other governmental entities or geographic areas. Women in New Jersey will benefit most from initiatives and expertise within the State.

Now let me ask Ms. Hill to address the issue of stability of funding for breast cancer research.

ANN MARIE HILL: Thank you, Dr. August.

We are actually going to be a partnership today, and we will share some of the observations we have made. The first thing I want to say is that the New Jersey State Commission on Cancer Research is delighted to be a part of the Summit report. We gladly accept the responsibility for the research section. We are delighted to be working with The Cancer Institute on therapeutics, and the other sponsors, indeed, everybody in this State on this important goal, which is to reduce breast cancer mortality.

Within the research section there are many, many issues and policies and, Assemblywoman Weinberg, I will not report on all of the progress, but please be assured that we have, very vigorously, been pursuing many of the avenues. We did want to highlight three issues:

The first one is the need for funding for cancer research. There is no doubt, if you have reviewed the report, that you recognize that breast cancer research is a very high priority. New Jersey has lagged behind neighboring states in its ability to attract national funds back to the State. We have done surveys of National Cancer Institute funding. New Jersey, basically, is able to attract from the NCI \$.15 per person. New York, Pennsylvania, and Connecticut all attract far more than that: New York, \$1.11 per person, Connecticut, \$.41 per person, Pennsylvania, \$1.15 per person. Yet, New Jersey has, of all of these states, the highest breast cancer rates. This is simply not acceptable, and we must take steps.

Now, you have reviewed, I know, the Summit report. You have seen the needs of research. David has talked about some of those needs: basic research, transnational research, clinical investigations and trials, epidemiology, psychosocial research, and cancer prevention and control studies. These all need to be studied. This is a very heavy and expensive agenda.

Now, while these needs are great, we do have some very exciting solutions. You have heard a little bit about them today already. We have a new checkoff on the State income tax that begins this year. The Breast Cancer Research Fund offers a very important opportunity to the citizens of this State to demonstrate their commitment to the fight against cancer. It will help start attacking many of the needs that we just listed. We applaud Assemblywoman

Heck, Assemblywoman Vandervalk, and others in this group who I know have worked hard for that Fund. I am especially proud of our Breast Cancer Advisory Group. If you could ever see the energy and creativity that that group has brought to this Fund, it would truly astound you. I congratulate all the members for their success. They have already kicked off the Fund with a fund-raiser. They have already laid the groundwork to really promote the Fund. It needs to be promoted.

But I have to warn you, by nature breast cancer research, cancer research, requires a long-term commitment and its support must be continuous to be successful. The average NCI grant is three to five years. A training fellowship is three to four years. Clinical trials can take ten years to complete. Epidemiological studies also require huge amounts of resources and time. While I am extremely positive and optimistic about the Fund's ability to raise some necessary resources, I do have to tell you that other strategies may be necessary. The road we follow is a long one. It is arduous, and it will require our full determination and stamina to complete. But if we do fulfill this effort, I have no doubt that we will be able to accomplish a great deal in New Jersey.

I told you we were partners, so I am now going to ask Dr. August to talk a little bit about data needs.

DR. AUGUST: Another critical need beyond funding for the advancements of cancer therapeutics and research within the State of New Jersey is improved data collection and distribution. As you know, the Department of Health has recently made great progress on updating and improving capabilities of the statewide tumor registry. Because of the enormity of that task, and the limited resources available to accomplish it,

however, it is likely that the data collection capabilities that will be necessary to have a dramatic impact upon breast cancer mortality in this State will be a long time coming if we do not do something more.

The Department of Health is doing an excellent job, but the Breast Summit report identifies data needs for breast cancer research and treatment in the State that will not be met by currently funded efforts. Targeting of additional resources to assist the Department of Health in meeting some specific needs for breast cancer can accomplish two major purposes: First, it can hasten the impact of improved data collection on breast cancer mortality and, I think just as importantly, improvement of breast cancer data collection can be used as a model by which the entire statewide tumor registry can be updated and improved to improve all cancer care.

Let me just briefly give you four specific examples of the kinds of data I am referring to: First, there is no current ability within this State to know the exact size, extent of lymph node involvement, and nature of potential cancer spread in breast cancer patients statewide. Such so-called TNM staging data are currently not available to researchers. High-quality clinical research simply cannot be performed without access to such data on a statewide basis.

Second, as hard as it may be to fathom, there are no up-to-date data on breast cancer survival on individual patients in the State. Therefore, it is very difficult to answer broad questions concerning the efficacy of certain treatment modalities and the effect, for instance, of a multidisciplinary team approach to breast cancer care, something that many of us believe in, a

problem that I think is crucial. The effect of those kinds of initiatives on breast cancer mortality statewide simply cannot be measured currently.

Third, on a statewide basis, there is no way to identify exactly what kinds of treatments the patients have received. Once again, this leaves clinical researchers in the dark as to where potential improvements might be made and potential treatment advances might be found. As a specific example, there are no current data concerning the use of breast reconstruction in this State, and a crucially important issue relating to quality of life in breast cancer patients.

Finally, there are no statewide data available concerning participation in clinical trials. We currently have no way of identifying which patients are on clinical trials, what clinical trials people are participating in, and the relative success or failure of these trials. All of these kinds of data can be easily collected with an updated approach to a statewide tumor registry, a task that will require an ongoing commitment of resources.

Speaking of clinical trials leads me to the third and final issue that Ms. Hill and I wanted to bring before you, namely, facilitation and support of clinical research trials within the State. Quite simply, today's best care is a result of yesterday's clinical research trials. If we are to prevent women from dying of breast cancer the way they are today, we need to discover tomorrow's treatments through clinical research now. Such support could essentially be in the form of creation of support structures to facilitate access to and participation in clinical trials by breast cancer patients, particularly minorities, an underserved group in this disease.

A major current frustration that I have as a clinical researcher is the reluctance of managed care entities to fund patient participation and clinical research. Unlike insurance coverage in the past, many insurers now feel that if a patient is placed on a clinical trial, they refuse to pay for any of the care provided to that patient, even if much of that care would have been necessary had the patient not participated in the trial. Something needs to be done about this.

Let me, once again, turn the microphone over to Ms. Hill to discuss some potential initiatives in this direction.

ASSEMBLYWOMAN VANDERVALK: That is just what I was going to ask you. You are making recommendations to tack on to what you just said?

DR. AUGUST: Yes.

MS. HILL: We are certainly going to try to.

We have recently seen, with some leadership from Assemblywoman Heck, the issue of genetic privacy passed as a critical bill for the State of New Jersey. This issue was compelling, the stakes were high. The legislative response was strong and swift. In the same light, the need to make clinical trials more accessible to women with breast cancer in New Jersey is equally urgent and demanding.

New Jersey is seriously behind the national averages in our ability to approve patients on clinical trials. The Commission did a survey -- and does surveys quite regularly -- that indicates that only roughly 2 percent of New Jersey's patients who are eligible for clinical trials are actually enrolled. National averages tend to be 4 percent to 6 percent. You have heard Dr.

August tell you that clinical trials offer the very best care a woman can receive. They are the gold standard, yet the emphasis on reducing health care costs has rendered a serious threat to clinical research. Limited or no payment for routine care associated with clinical trials is rapidly becoming the standard practice among insurance companies, particularly some of the HMOs.

ASSEMBLYWOMAN VANDERVALK: Excuse me.

MS. HILL: Yes?

ASSEMBLYWOMAN VANDERVALK: I am very reluctant to interrupt, but on that particular point, you are making it sound like it is changing, that there had been coverage--

MS. HILL: Let me try to explain that. In the past-- It is not absolutely changing, but we are finding that it is more of a struggle as we find ways to manage our health care costs. So, traditionally, HMOs have covered some of the standard things that we might use in a clinical trial, some of the additional tests that might be required. It is not necessarily the new drug that is not being covered, or the new therapy itself. It is the other things that are absolutely essential to fulfill the requirements of that clinical trial that are often rejected.

DR. AUGUST: If I may just give--

ASSEMBLYWOMAN VANDERVALK: But the point is, that is changing. There had been coverage?

MS. HILL: There has been more of a movement-- We are seeing more of a movement toward less and less coverage for clinical trials.

DR. AUGUST: If I may just offer an example: In the past, if a patient was on a clinical trial that required a chest X ray to be performed, and

that chest X ray would have been performed had they not been on the trial, that would have been covered by the insurer. There is more and more difficulty now in even getting those standard kinds of investigations covered, merely because being on a research trial is an excuse to not cover it.

ASSEMBLYWOMAN HECK: Assemblyman Pascrell?

ASSEMBLYMAN PASCRELL: Thank you.

I would like to follow up on Assemblywoman Vandervalk's question, because I know we have legislation before us that attempts to -- not suffocate, but regulate, so that people are protected. We are hearing more of this in many areas. It seems to me that we declared war -- this nation declared war on cancer in 1972, and if we really mean that, then perhaps in New Jersey, as we broke ground, for instance, in the area of Agent Orange, we may, in our own State, declare war and mean it and take no prisoners.

MS. HILL: Sounds great.

ASSEMBLYMAN PASCRELL: Because investment in the technology is critical. It is an investment in the future. When you look at the maps that came out at the Summit, I mean, is it simply coincidence that the eight or nine states in the Northeast are leading the nation in the mortality rate in terms of breast cancer? I don't think-- I mean, look at math. I understand that math and science-- I don't think it is a coincidence.

Given that, we need to be looking at ways to educate so that we can prevent these things from happening. Assemblywoman, you said it toward the end, that what we are talking about is controlling costs. This is part of the health care machine that we need to address if we are going to control those costs. It doesn't matter whether it is covered or not. In the long run, it does

not matter if it is covered or not if the cost has gotten out of reach. We need to control the costs.

So education is critical -- obviously, that was the mainstay of your Summit -- and prevention, because not only does it help people to stay alive, but it reduces the costs.

Have you concluded as to what reasons the Northeast leads the entire rest of the nation?

ASSEMBLYWOMAN WRIGHT: But it doesn't, Assemblyman. You are not looking at the data correctly.

MS. HILL: Not necessarily, but go ahead.

ASSEMBLYMAN PASCHELL: Well, the State seems to be-- The mortality rate--

ASSEMBLYWOMAN WRIGHT: The incidence rate, though, is different. There are two charts.

ASSEMBLYMAN PASCHELL: I am looking at the mortality rate.

ASSEMBLYWOMAN WRIGHT: Look at the incidence rate.

ASSEMBLYMAN PASCHELL: Right.

MS. HILL: Incidence and mortality are different.

ASSEMBLYWOMAN HECK: Ann Marie, do you want to answer the question?

MS. HILL: Why mortality is high in the Northeast? I am going to be honest. It may be our population mix as well. We have looked at some of the reasons, and we believe the type of demographics we have in the east, and also the fact that we are an industrialized area in the east, we are urbanized, we have a more concentrated population, we have lifestyles that

may affect incidence rates-- These are all factors. The truth is, we don't know what causes breast cancer, so it is very difficult for us to actually determine what reasons may exist in one area or another. But we are going to presume that in breast cancer mortality, a lot of it is the area -- the traits of the Northeast area, being industrialized, being heavily populated.

I honestly believe that it is our ability to bring the best care that will also help to reduce breast cancer mortality. That is something that I want to see in New Jersey.

ASSEMBLYMAN PASCRELL: Thank you.

MS. HILL: I just want to make a quick point: There was great fanfare the other day. I am not debating the pluses and minuses of this, but there was great fanfare by some of the HMOs when they announced that they will now be covering alternative medicines as part of their insurance coverage. I really wonder why methods such as alternative medicines, good or bad, but unproven, are covered, but many of the simple costs of participation in a cancer research trial are not covered.

I would argue that if we are going to do a good job in medicine, a cost-effective job in medicine, the medicine has to be science driven. It is incumbent upon us to take actions in this regard now. The National Action Plan on Breast Cancer, the President's Cancer Panel, representatives from the National Cancer Institute have all voiced the same concern. Other states are beginning to look at this issue very seriously, not just one experimental treatment, not just bone marrow transplants for women, but looking at this issue as a whole.

Now, we know that mandates are often raised as a possibility, but certainly Dr. August, myself, and the sponsors would be very, very willing to explore any new and innovative avenues and strategies that may address this issue. It is a difficult challenge. The important ones always are, but the fact is, we must take action on this one. As legislators who I know are very concerned about this whole process, we would really look to you for some leadership in this regard.

ASSEMBLYWOMAN HECK: Through the Chair, Assemblyman.

ASSEMBLYMAN JONES: I wouldn't have it any other way, Madam Chair.

Through the Chair, you mentioned in your -- the young lady-- I'm sorry, I didn't--

ASSEMBLYWOMAN HECK: Ann Marie Hill.

ASSEMBLYMAN JONES: Ms. Hill, you mentioned -- through the Chair -- in your earlier statement that New Jersey was lagging behind with respect to national funds. I would assume you were speaking research funds.

MS. HILL: Breast cancer research funds, in this case, but also general cancer research funds. We have improved, but we are still lagging behind.

ASSEMBLYMAN JONES: I am just curious, you know, since you have been keeping track, how far, in terms of dollars, actual national dollars, has New Jersey not been able to take advantage of since you have been keeping track of such statistics?

MS. HILL: Not taken advantage of? In that case, the world is the limit, because, depending on the breadth of our research infrastructure, the

quality of our researchers, and the commitment we make as a State, there is a huge -- billions of dollars available for cancer research, and hundreds of millions of dollars available for breast cancer research.

We have a young research infrastructure. David can tell you that The Cancer Institute of New Jersey is trying to become a comprehensive cancer center. That will help. The Commission on Cancer Research has been very carefully working, with very limited budgets, to also make that research infrastructure grow. But there is a huge amount of money available for breast cancer research and cancer research. I would say to look at the neighbors, Pennsylvania, New York, Massachusetts, and Connecticut, and see how much money they are attracting, but they have an infrastructure. You heard Jeanne Beck talk about one strategy. There are huge strategies presented in this report, and we have not even touched on serious prevention research, ideology research. We have an enormous job to do. Every step we take gets us closer and closer.

The fact is, the State of New Jersey has to invest its limited resources wisely so that it can bring back all those national funds.

ASSEMBLYMAN JONES: Through the Chair, so, at this sitting, you do not have an idea of what the quantitative loss has been in national dollars?

MS. HILL: To answer that, I could tell you that, from the Commission's experience, we give seed grants. Okay? We give very small grants out to investigators with bright ideas, but they do not have any Federal funding yet. We will give them just enough money to get started. Then, we expect them to be able to go to the national government and bring that money.

We have a very stringent auditing process on this. We get \$3 back from the Federal government for every \$1 we invest. I would like to see a bank account that does better than that.

ASSEMBLYMAN JONES: Okay.

Lastly -- through the Chair -- the whys behind the lagging of being able to take advantage of national funds-- As you indicated, if I am understanding correctly, it is because of the very young infrastructure that is in place and, you know, that is beginning, obviously, to evolve. But also, from the State's perspective, has the State of New Jersey done all that it should have done or could do in order to attract the national dollars that are perhaps eligible for research purposes?

MS. HILL: In all honesty--

ASSEMBLYWOMAN HECK: That question will always have the answer that we want it to have.

MS. HILL: Yes.

ASSEMBLYWOMAN HECK: There is always a need for more.

MS. HILL: There is an absolute need. The Commission has \$1 million for clinical -- or, for cancer research in general. I am told the breast cancer research funds-- They laughed at Treasury when I said we would be the number one fund shortly, but they told us to expect \$250,000. I'm sorry, that is a drop. That is not even a drop.

So are we doing enough? No, we have not done enough, and we need to do plenty more. The groups here are ready to do that, but we will need your support.

ASSEMBLYMAN JONES: Thank you.

ASSEMBLYWOMAN VANDERVALK: I know there are a lot of people waiting to testify yet, but Assemblywoman Wright has asked for the floor.

ASSEMBLYWOMAN WRIGHT: I just have to keep reiterating my conundrum, I guess, about how the data are presented and where the problem is greatest.

The other question is: When you talk about New Jersey data-- I mean, national data are what you use to treat, right, in terms of how we approach-- You need a--

MS. HILL: In terms of clinical trials, we would expect clinical trials to be done nationally. So, in that sense, we are evaluating at the national level. What David is talking about -- and he may want to answer it -- is specifically looking at what is happening in New Jersey for us to determine whether we are doing a good enough job or not.

Just as an example, we have talked about early detection and mammography. It is very hard for us to measure success in that regard. We talk about surveys with 40 percent of doctors recommending mammography. What we need is a real way to measure it. This is not an easy thing to judge, but as a group we felt that if we could use tumor size at diagnosis-- This is something measurable. We could track this. That is not something that is available, however, at this time.

ASSEMBLYWOMAN WRIGHT: I think it is the other mike you need, Dr. Wallner.

DR. WALLNER: Well, I can shout.

If I may make one point, Assemblywoman Wright, I think you are on the right track, in the sense that it is true that national data has analogies to how we treat patients in New Jersey. So national clinical trial data is valid for us to make decisions, but there is a second, more subtle issue that we have not really brought up this afternoon. That is, there is clear data that women on clinical trials for breast cancer do better in survival, long-term survival, than women who are not on clinical trials. There are all kinds of issues related to why that is, whether they are simply receiving a standardized level of care, better oversight, or better care, but we need more women on clinical trials, both for the answers and for the therapeutics.

ASSEMBLYWOMAN WRIGHT: I guess the next question I see in the data that I am looking at is: New York and Pennsylvania have almost as high rates of mortality as New Jersey. Now, that is rates based on incidence, so they have actually fewer cases of patients who die?

DR. WALLNER: Per capita.

ASSEMBLYWOMAN WRIGHT: Oh, that's per capita. It is not per incidence then.

What I am saying is, there are fewer cases of breast cancer -- if I am reading this correctly -- in Pennsylvania and New York, but they have comparable death rates.

DR. WALLNER: Those are all standardized populations.

MS. HILL: So you can compare them.

DR. WALLNER: Usually they are per 1000 or per 100,000.

MS. HILL: So they are not just raw numbers. What you are seeing is a ranking. It is a ranking.

ASSEMBLYWOMAN WRIGHT: Right. Then the question I have is: It is curious to me that there is-- Well, maybe it isn't. I'll hold my question.

ASSEMBLYWOMAN VANDERVALK: Assemblywoman Weinberg?

ASSEMBLYWOMAN WEINBERG: First of all, I know I keep on coming back to the cancer registry. But both Ann Marie Hill, from the Research Commission, and The New Jersey Cancer Institute were an enormous help in trying to get a handle on the problem that has existed in data collection in New Jersey. It is certainly not a problem with this administration. They inherited it. It happened over a number of years.

I am a little bit concerned, though, Doctor, on this in terms of some of the problems you raised. Very recently, we passed legislation which was signed into law to give additional funding to the New Jersey Cancer Registry which, based on the information that they gave us, was supposed to be sufficient to bring the registry up to date.

I have been asking the Department of Health for a timetable. I received a short letter back that they expect the backlog to be completed by December 31, 1996, the end of this year, and that a published report of cancer rates through 1995 will follow soon thereafter in early 1997. Cancer rates by county, municipality, and zip code may take somewhat longer to generate.

I am wondering if they are overlaying the information that you say you are going to need, or that I think I heard you talk about -- whether that is being considered as they try to get this backlog up to date.

DR. AUGUST: The Department of Health is going to have a chance to testify, so I think some of these questions ought to be directed to them. I would just highlight two issues: One is, even when they are up-to-date, the data that they will be able to report effectively will still be at least six months and, in many instances, more than a year out of date. In a fight this crucial, that is a real handicap.

But, secondly, the capabilities that they will have to report up-to-date information on limited amounts of information, not getting at many data items that are absolutely crucial if we are going to understand what the breast cancer problem is in this State to be able to target specific problems for solution, and then effectively and in a timely fashion evaluate whether our intervention really had an impact-- Even if they do everything they are planning to do, there will still not be the data necessary to pursue the agenda laid out in the Summit report.

ASSEMBLYWOMAN WRIGHT: Then, based upon what I thought I heard you say to the Chair, they need to do more. Maybe they are going to need more money. Maybe they are going to need more hardware or software. But the planning is far from complete -- what they are planning to do right now.

DR. AUGUST: That is certainly my understanding, yes.

ASSEMBLYWOMAN WRIGHT: When they testify, I would hope that they would address some of the issues that you raised. Perhaps when we hear from Dr. Ziskin, or whomever is going to testify, they will address some of these issues. I am concerned that maybe we have not given them the

resources that are needed, although I thought we were giving them the resources that they asked for.

I do not believe we are going to get anywhere near the bottom of this problem until we are working with the proper data that the scientists and the practitioners in this State need to make judgments, along with the patients themselves.

ASSEMBLYWOMAN HECK: Assemblyman Jones?

ASSEMBLYMAN JONES: Thank you, Madam Chair.

You know, through you, again, I think the appropriate thing is for this Joint Committee to perhaps look at something that Assemblywoman Weinberg talked about, and that is the cost issues, but perhaps even the establishment of a bipartisan commission that will establish the appropriate infrastructure that would begin to address these issues of cost.

We understand what the data says in terms of the mortality tables, the incidence tables, and all those things. We are working our way back to a very common denominator, and that common denominator is the denominator of cost. Until we begin to just lay out the fundamental foundation of an infrastructure, perhaps through a bipartisan commission, to address these issues, we are going nowhere. We are going absolutely nowhere.

ASSEMBLYWOMAN HECK: Oh, I beg to differ, Assemblyman.

ASSEMBLYMAN JONES: Oh, this is not a criticism.

ASSEMBLYWOMAN HECK: No, no, we are having a Joint Committee hearing to expedite the findings of the Summit. We have not done this lightly.

ASSEMBLYMAN JONES: Madam Chair, and I say this with all due respect, and I say this, I believe, with the support of the people in the audience -- and I would hope your support also-- Don't get offended, because it is not a criticism.

ASSEMBLYWOMAN HECK: I am not offended. It is just a surprise to me.

ASSEMBLYMAN JONES: I hope it is a pleasant surprise. But, you know, this is merely a recommendation to establish something that I believe would begin to address one of the things that we constantly find ourselves all the way back to, and that is the issue of cost. I think it is an appropriate recommendation. I would hope that it would find its way to the ears and the hearts of the members of the Committee to weigh and begin to establish such a body, or if this becomes the bipartisan commission to address these issues--

ASSEMBLYWOMAN HECK: We are the body and we are bipartisan.

ASSEMBLYMAN JONES: Well, again, Madam Chairlady--

ASSEMBLYWOMAN HECK: That is what I am trying to tell you.

ASSEMBLYMAN JONES: You know, in the spirit of just trying to do what's right, that was merely a recommendation that I saw fit to make. Again, it was certainly not anything that you should take offense to--

ASSEMBLYWOMAN HECK: No, I know that.

ASSEMBLYMAN JONES: --but merely something that I think would be beneficial to the folks who are here today.

ASSEMBLYWOMAN HECK: Excuse me, sir. Excuse me, Mr. Jones.

ASSEMBLYMAN JONES: Thank you, Madam Chairlady. I am signing off now.

ASSEMBLYWOMAN HECK: Thank you.

I just wanted to point out to the body that this is not a debate. We are all in agreement. That is why we are here today. I mean, just so that you are aware, this is a bipartisan effort in a Joint Committee forum. I think we are doing a spectacular job. We are honing in on what we must do as a next step. We are already involved with several issues that we are working on. If we allow the testimony to continue, we will probably be enlightened even more so.

Thank you.

Dr. Wallner, thank you.

DR. WALLNER: Thank you very much.

The New Jersey State Department of Health and Senior Services has accepted the obligation and task of directing and assuming a leadership role in the areas of early detection data collection and dissemination. I don't believe that Dr. Ziskin is here today, but Dr. Elin Gursky is the Senior Assistant Commissioner for the New Jersey Department of Health and Senior Services. I believe several of her senior staff people are also here.

SCOTT ALLOCCO: My name is Scott Allocco. I am the Director of Government Affairs at the Department of Health and Senior Services. I would like to suggest that we have two different issues. I would like -- with your approval -- to start with Dr. Elin Gursky, Senior Assistant Commissioner

at the Department of Health and Senior Services, and Betsy Kohler, Director of the Cancer Registry. We would like to have an opportunity to discuss many of the issues that have been raised today and to speak about the success -- the legislative success and changing the rules on cancer reporting and our abilities to report information more effectively.

Before they begin, I would like to thank the members of both Committees for holding this hearing today. On behalf of the Commissioner of Health and Senior Services, we certainly appreciate your efforts today.

I would also like to thank Assemblywoman Heck for her sponsorship -- in fact, sponsorship of the genetic testing and privacy bill. It does have substantial implications for the clinical trial issue that was just discussed. I did want to thank you personally, Assemblywoman, for your support to make that a better bill to ensure that clinical trials in New Jersey are, in fact, promoted.

On that note, I would like to turn the microphone over to Elin Gursky and Betsy Kohler to discuss the status of the New Jersey Cancer Registry.

SENIOR ASST. COMM. ELIN A. GURSKY: Thank you very much. I have been introduced twice, so let me just thank the Assembly Health Committee and the Assembly Policy and Regulatory Oversight Committee for holding this joint hearing on implementing the Breast Cancer Summit recommendations.

I would like to begin my testimony by updating you on some statistics regarding breast cancer in New Jersey. During the period 1988 to 1992, the latest for which national data are available, New Jersey's breast

cancer incidence rate went 7th among 37 state and regional cancer registries included in the "Cancer Incidence North America," published by the North American Association of Central Cancer Registrars. This differs from the data in your packet, but the important thing to remember is that New Jersey continues to have very high breast cancer incidence rates.

During the same time period -- 1988 to 1992 -- New Jersey ranked third in breast cancer mortality in data published by the National Cancer Institute. New Jersey's breast cancer incidence rate for this period was 112.7 per 100,000 for white females, as compared to the U.S. rate of 107.4 per 100,000, and 90.2 per 100,000 for New Jersey African-American women, compared to 90.5 per 100,00 for the United States.

Data comparing New Jersey incidence rates with other nearby states indicate that New Jersey has similar rates to Connecticut and Delaware, and slightly higher rates than Maryland, Pennsylvania, and perhaps New York. By far, more cases of breast cancer are diagnosed among women than any other cancer. Breast cancer represents about one-third of all the cancers diagnosed among women, and about 15 percent of all case reports to the Cancer Registry. Breast cancer incidents continue to rise with age. White women tend to have higher rates after age 40 when compared to African-American women, but African-American women have higher mortality rates.

Obviously, we must do better. We must have more accurate, timely information on breast cancer data. I am pleased to report that due to new Cancer Registry legislation -- which was discussed earlier -- we are well on our way to meeting the Cancer Registry's goals at the last Breast Cancer Summit. Legislative changes in July of this year have significantly

strengthened the ability of the State Cancer Registry to do its job. Prior to the legislative changes, the Registry had no recourse if a health care facility did not report cancer data on time, and without complete data from all hospitals, the New Jersey State Cancer Registry cannot publish incidence rates.

Now, if a hospital fails to report cases on time, the Department has the statutory authority to charge up to \$500 per unreported case. Further, any facility not reporting cancer cases electronically by the end of this year is subject to a fine of up to \$1000 per business day. Obviously, these goals are not for us to generate funds. We think this will be an incentive for hospitals to do the reporting we need them to do.

Another major tenet of the legislation is a requirement that data be prepared and submitted from health care facilities by a certified tumor registrar. This requirement will help to guarantee the quality of the data submitted to the Cancer Registry, since a certified tumor registrar must pass a national examination process. Having a certified tumor registrar on staff at all New Jersey acute care hospitals was one of the four recommendations by the Summit. We have gone a step further to require that all data are submitted by a certified tumor registrar.

A third aspect of the legislation appropriated \$400,000 to the Registry to work on the elimination of the data backlog and establish an infrastructure of epidemiologists to provide improved cancer surveillance. Thanks to this appropriation, we will be able to reduce the backlog by December 31 -- as Assemblywoman Weinberg just said. We will be complete through 1995 data by December 31.

The hiring of cancer epidemiologists will mean that this will not be a passing database. It will be an actively used database where we study the data, learn from it, and do the appropriate screenings and other activities.

The Department has also been working with Congressman Chris Smith's office to draft language to strengthen the Federal Cancer Registry Amendment Act. Proposed changes include requiring the reporting of cancer cases by all Federal and VA hospitals back to the state registry of residence, so that New Jersey can count cancer cases among our citizens stationed throughout the country. Other changes seek to acquire exchange of cancer registry data among states in a standard format and in a timely manner.

Congressman Smith has advocated for increased funding for the national program for cancer registries so that states like New Jersey can continue to use Federal funds to enhance these invaluable resources for cancer surveillance and research.

A recommendation repeated throughout the Breast Cancer Summit report calls for expanded on-line access to cancer registry data. The New Jersey State Cancer Registry is working with the New Jersey Commission on Cancer Research and the research community, including The Cancer Institute of New Jersey, UMDNJ, to develop a system that allows appropriate access to cancer data while maintaining patient confidentiality. Furthermore, staff has been in contact with officials from the Centers for Disease Control and the North American Association of Central Cancer Registries, and several other states in developing such a system. We expect to receive the plans for this system more aggressively once our backlog has been completed.

Training of the research community will be held next week on the registry database, how to access cancer data, and a simplified public use data set. A second training will be held for legislative aides and the public in two weeks. Long-range plans include Internet access by aggregate data and a statewide database designed for access by cancer researchers.

The Summit report also called for expansion of the cancer registry data set. I am pleased to report that through implementation of the new PC-based computer system, the Registry will be accepting certain key variables not collected before. They were just discussed. For example, the TNM -- tumor node metastasis staging system -- will begin to be phased in by hospitals already collecting this data. It is already collected by most major hospitals and those with cancer programs accredited by the American College of Surgeons. Likewise, the State Cancer Registry will be able to report other data collected by these facilities, such as tumor size. I know that was stressed just before coming here. We will be doing that.

Treatment data is now collected, once again, as the first course of therapy for all cases diagnosed after January 1, 1995. The Registry conforms with all data standards of other central cancer registries and the Centers for Disease Control and Prevention, which sponsors the national Program for Cancer Registries. To collect, edit, and report on data that are not part of the national database, and for which national standards do not exist, would be costly to the State health care providers. We will consider specific proposals for their related costs. We will always strive to continue to meet national standards for cancer data collection.

The Director of the Office of Cancer Epidemiology, Betsy Kohler, to my right, is currently serving on the Board of Directors of the North American Association of Central Cancer Registries. She is helping to develop new policies related to data standards and tracking national trends in data collection.

Improved reporting of cancer by nonhospital sources was highlighted by the Summit recommendations. Nonhospital sources are becoming increasingly important for the Department as more cases are diagnosed and treated outside of hospitals. We have made progress on this recommendation by targeting physicians and independent clinical laboratory reporting. Staff has begun a major educational campaign targeting physicians to remind them of their responsibility to report cancer cases not seen in a hospital. As a result of this process, physician reporting has increased.

Simultaneously, staff is working on several national and local committees to standardize reporting formats for laboratories. This will enable those laboratories across the country to report to the registry electronically. Obviously, electronic reporting is going to be far more timely reporting.

Two recommendations dealt with improving training opportunities for epidemiologists and tumor registrars. We have moved ahead on both of these recommendations. The Registry is currently sponsoring a master's level student on an independent research project, and a Jack Rutledge fellow was placed, this summer, on a cancer-related project concerning the development of a cancer buster protocol.

We have been working with the Tumor Registrars' Association of New Jersey to sponsor a review course for tumor registrars planning to take the

certification examination. This review was so successful that we plan to offer it twice a year for each exam. Additionally, the Registry has been working with State and national partners to develop a formal tumor registry training program in this State at the college level. Progress is being made and we hope to have a full-fledged accredited program in New Jersey within the next year.

Finally, I would like to inform you that organizationally we have made a change by establishing a new Office of Cancer Epidemiology. This Office reports directly to me and it will focus greater attention on the use of cancer data collected for us to understand far more about cancer than we know now. Renewed emphasis will be placed on collecting the data in a high-quality and timely manner, but also to enable us to answer some of the questions that we are all asked: Which of our populations are at risk, and how can we impact on these?

Breast cancer research has been a fundamental aspect of the activities conducted by this group over the past several years. To date, six peer review papers have been published using breast cancer data collected in New Jersey. I would be happy to provide the Committee with abstracts or the papers. These publications address risk factors such as: oral contraceptive used, breast feeding, body size, breast enlargement and reduction, insight to an invasive breast cancer, and the role of induced abortion. Reports submitted for publication include: examination of alcohol consumption, preexisting medical conditions, pre- and perinatal risk factors, smoking, electric blanket usage, physical activity, racial differences in risk factors, diet, and biological workers.

I think I can say for Betsy Kohler and her staff that we are working very hard to address the issues raised in the Summit report. Clearly, we can always do more. We look forward to the suggestions you will be providing us.

I would be happy to answer any questions you might have.

ASSEMBLYWOMAN HECK: Does Betsy wish to speak as well?

B E T S Y A. K O H L E R: She said it all.

ASSEMBLYWOMAN HECK: I know that Assemblywoman Weinberg is very interested in asking you some questions.

ASSEMBLYWOMAN WEINBERG: First of all, Doctor, can we have copies of your very complete testimony?

SENIOR ASSISTANT COMMISSIONER GURSKY: I would be happy to send those to the Chair.

ASSEMBLYWOMAN WEINBERG: Thank you.

What do we do about -- since we have so many people here who probably get treated in New York or Pennsylvania hospitals-- What are we doing about reporting requirements? I guess we would need Federal legislation to regulate that.

SENIOR ASSISTANT COMMISSIONER GURSKY: We have very comprehensive reporting requirements for our residents who are treated out of state. We have reporting agreements with New York, Pennsylvania, Florida-- What state have I left out?

MS. KOHLER: Delaware.

ASSEMBLYWOMAN WEINBERG: So they are cooperating?

SENIOR ASSISTANT COMMISSIONER GURSKY: Very much so, very much so.

ASSEMBLYWOMAN WEINBERG: Okay, good, because I get all kinds of anecdotal complaints from people about that.

MS. KOHLER: That is an area of concern of ours, but we do exchange data with those other states. It is a little later in coming in, because it first goes to their registries. It depends on how up-to-date their registries are before we get it back. But we do eventually get it. We also look at the data from other aspects to try and fill in any gaps. That is one of the reasons why multiple reporting sources are so important to us.

MR. ALLOCCO: It is also important to note that the national legislation does not require interstate reporting. In Dr. Gursky's testimony, she mentioned that Congressman Smith is very interested in rendering a Federal law to make it easier for states to report their respective cases on a 50-state basis, so that we do not have to have these depending on state agreements.

ASSEMBLYWOMAN HECK: Perhaps this Joint Committee can put through an AR recommending that that be done in a very strong way, so we can all join in on that.

ASSEMBLYMAN JONES: It sounds great to me, Madam Chair.

ASSEMBLYWOMAN HECK: Good -- in a bipartisan way.

ASSEMBLYWOMAN WRIGHT: Dr. Gursky, I am not sure who in your Department should be answering this question, but I am still very interested in the earlier presentations about the relationship between clinical trials and the outcomes in terms of breast cancer. I don't think that because you get better outcomes in clinical trials you should do more clinical trials necessarily.

I just wonder: Where do we go with that kind of a question?

SENIOR ASSISTANT COMMISSIONER GURSKY: I believe -- Betsy can correct me -- 2 percent of our patients are now on clinical trials.

ASSEMBLYWOMAN WRIGHT: Yes, but 4 to 6 are nationally. There is a feeling here from the experts that the national results in states where there are clinical trials are better. I can accept that on one hand, but I don't think you do research to get better-- I mean, that is not the purpose of the research, right?

SENIOR ASSISTANT COMMISSIONER GURSKY: I think clearly that looking at our outcomes is an important component to what the Registry does. We publish annual vital status reports. I don't believe they are broken down by whether they participated in a clinical trial. We do not have that broken down.

DR. WALLNER: I think you can consider that as a beneficial spin-off of the clinical trials. It is not an end in and of itself. With clinical trials, the end result is, hopefully, to gain knowledge for the next step in treatment. But it is an appropriate beneficial spin-off. The patients on clinical trials tend to do better than those who are not on clinical trials.

ASSEMBLYWOMAN WRIGHT: But I think we are in the policy business of treatment outcome. I think Assemblywoman Vandervalk opened with some of her concerns about the length of clinical trials and the problems we are enduring already. I was just hoping that-- I am a very firm supporter of research, but I don't want us to believe that increasing the clinical trials will get the outcomes we want. It just does not make sense to me.

I hear what you're saying. You know, it is a serendipitous in its positive overtone, but I want to get at treating the patients.

DR. WALLNER: There is another, if you will, spin-off issue of clinical trials that really was, in some respects, to be discussed by Dr. Klein, and that is the issue of practice guidelines. For practical purposes, clinical trials are practice guidelines, because physicians who have patients entered on clinical trials have to follow very, very strictly those parameters, time parameters. Patients who are not on those clinical trials are treated, very often, in rather randomized, haphazard ways. So it is a form of a practice guideline.

ASSEMBLYWOMAN WRIGHT: Through you, Madam Chair, I think we are talking about protocols now. Also, back to the early detection protocol, the fact -- and I am not sure that the earlier report you gave us about 40 percent of the people that are referred from them-- I mean, we don't know what age those people were or any of the other data related to that survey you talked about. But if 60 percent of the people -- knowing the physicians in New Jersey -- are not being referred and they should appropriately be referred, you know, that is a bigger question. I don't know that from the limited information we have.

DR. WALLNER: That particular report that Dr. Wenger alluded to was generated by the Ohio Division of the American Cancer Society. That is not New Jersey data. In that report, 98 percent of the physicians queried agreed with the American Cancer Society guidelines for mammography screening, but only 42 percent actually followed the guidelines. So they believe in them, but they are simply not sending the patients for mammography.

ASSEMBLYWOMAN WRIGHT: Which is a whole other question.

ASSEMBLYWOMAN HECK: It might be appropriate to say that Dr. Klein was called back to her practice, so I will tell you that she gave me some information that The Medical Society is going to do an outreach to all the physician members of The Medical Society to impress upon the physicians that they really should recommend mammographies on a routine basis. Another important point she wanted to make clear was that they will also be reaching out to the younger population, saying that they will be teaching and impressing upon teens that they should be doing self-examinations, because young people are victims of breast cancer, not just older people.

Assemblyman Jones?

ASSEMBLYMAN JONES: Madam Chair, did Dr. Klein have a prepared statement that might be shared with all of us?

ASSEMBLYWOMAN HECK: No, she did not, but we will make certain that The Medical Society gives us a copy of what their program -- what their proposed program will be. She said that they will cooperate, and have cooperated, with the Summit, but will also cooperate with any recommendations we might have at the conclusion of this particular hearing.

ASSEMBLYWOMAN WRIGHT: I just think, Madam Chair, that this is a very serious concern, because we can sit here, raise all the money, do all the research, but if we, as practitioners, are not following through, and that won't cost us anymore money--

ASSEMBLYWOMAN HECK: That is why we were very happy to hear that.

ASSEMBLYWOMAN WRIGHT: Thank you, Madam Chair.

ASSEMBLYWOMAN HECK: We will get written testimony to that effect.

DR. WALLNER: I am a member of the Council on Public Health of The Medical Society of New Jersey. I can assure you that this has been discussed. The Medical Society is committed 100 percent to the establishment of practice guidelines and standards for breast cancer care, and also for the educational programs that are in the Summit report.

ASSEMBLYWOMAN HECK: Are there any other questions for this part of the panel? (no response)

Thank you very, very much. I am very pleased that you were here to give that information to Assemblywoman Weinberg.

SENIOR ASSISTANT COMMISSIONER GURSKY: We were honored to be here.

ASSEMBLYWOMAN HECK: Thank you.

DR. WALLNER: We have two additional staff members from the Department of Health, Jean Marshall and Celeste Wood.

ASSISTANT COMM. JEAN R. MARSHALL: Good afternoon, everyone. We are delighted, also, to be here. I am Jean Marshall. I am the Assistant Commissioner of Health, Division of Family Health Services. This is Celeste Andriot-Wood, who works within my Division, who honchos, really, the breast and cervical cancer initiative. I have asked her to make some remarks, and then I will sum up after that.

I do bring you greetings, though, from Commissioner Fishman and Deputy Commissioner Leah Ziskin, who asked that I remind you all that they both take the breast cancer initiative very seriously. That is why we put a lot

of our energies toward working with Dr. Wallner, with the Cancer Society, with Cancer Research, really to help with this problem.

The Division of Family Health Services houses the Breast and Cervical Cancer Grant. It is \$2 million from the Centers for Disease Control and Prevention. Celeste is going to-- In the interest of brevity, she will be speaking about that, and then I am going to wrap up with what I think is so very important.

C E L E S T E A N D R I O T - W O O D: Thank you, again, and good afternoon. It is a pleasure to be here today. I am very pleased to be able to provide an opportunity to share with you what we have been doing with regard to the breast and cervical cancer control initiative.

We received a grant from CDC -- a comprehensive grant -- in January of 1996. At that time, there were five counties which were part of the project. There are now twelve counties, with three additional counties expected to be underway shortly. So we are moving forward. With our projections, we should be able to provide screening for about 4500 women. Our target is really women over the age of 50, minorities, low-income, uninsured, or underinsured women.

The projects, as you heard earlier when we first started -- when you first started the hearing-- The project in Bergen County is a collaborative effort. It is not an isolated screening project. It is a project which involves a lot of community effort, a lot of collaboration among community providers. Every county that we are working with from the project has multiple agencies which are involved. They are provided services through multiple hospitals, multiple advocacy organizations, and each has formed its own coalition which

then comes to the State level, which forms the Breast and Cervical Cancer Coalition. Through that entity, through that body, with representation, cross-representation from researchers, physicians, and advocates, we are preparing and planning for our program. We are looking at multiple outreach activities.

We, so far, have screened 800 women. Some of the things I have heard here today I think you may be interested in. As far as the numbers for those 800 women, over 20 percent had not received prior mammography. Additionally, 47 percent came into the program because of outreach efforts. Only 28 percent came in because they were referred by a physician.

The outreach efforts are designed and carried out at the local level. The successful outreach efforts have included a project which was started in Camden County, which is called *Where's Shirley?* I don't know if any of you are familiar with this. It is a play which basically depicts African-American women in a beauty salon discussing the benefits of mammography, early identification, and dispels some of the myths associated with breast self-examination or pursuing prevention types of activities in testing.

We are also targeting high-utilization areas as recommended in the Breast Cancer Summit report. As you may also be aware, the United States Postal Service issued a breast cancer awareness stamp. The post offices throughout the State have been very cooperative with local projects and in opening up their doors and allowing programs to set up and actually recruit women for screening who come in. Additionally, supermarkets have been very cooperative. So the efforts are grassroots efforts. There is not a mass media campaign, although we do have plans for a multicultural video which will

provide additional awareness. We are going to have women and men who have experienced breast cancer speak to their experiences and try to emphasize the need to get in for early detection and to go through routine screening as recommended.

Additionally, we have mobile mammography -- mobile mammography which, right now, is operating in about half of our counties -- which can provide a great opportunity to increase access. The mobile mammography programs go to senior centers, they go to senior housing complexes, or to other areas which are not readily accessible or where women cannot readily access screening services.

What do we need to do? Obviously, we need to continue to do a lot. We are going to be pursuing, certainly with the Centers for Disease Control, increased funding, if possible, in order to expand to the 21 counties in this State, so that we will have a collaborative project in each and every county so we can assure accessibility for low-income, minority women.

We also want to expand the use of mammography. Again, that takes resources. You heard and talked about the costs of screening. The project has been very successful, and the local projects have been very successful in getting cooperative relationships with the providers in their areas. They are accepting either the Medicare rate or the Medicaid rate, whichever may apply. We look to try to continue that effort.

We are also working to develop very aggressive outreach campaigns. The efforts cannot stop. We have been successful in getting women in, but we have to do a lot more. We particularly need to do a lot more in the minority communities.

We have, right now under the screening program, about 65 percent to 70 percent of women who are Caucasian, about 28 percent are black, and the remaining 7 percent or 8 percent are Asian and/or Native American. That is the way the racial/ethnic background is thus far.

We have now established a data system where we can track the women we are screening, so we are looking to get some very good information with regard to behavior and attitudes on referral, on information and how effective our education activities are. Again, I cannot stress enough the collaborative relationship between the Coalition members who are advising us on how we should pursue our planning and our educational and outreach efforts. We will continue to work very aggressively with organizations such as the New Jersey Division of the Cancer Society, the Cancer Research Commission, our sister divisions in Senior Services and Prevention Protection, as well as the American Association of Retired Persons, YWCAs, the list goes on and on.

There are a couple of subcommittees which are working on promoting and researching out what medical guidelines exist, and what we can implement through our projects to assure quality. We also certainly agree and want to work with efforts to assure that there is an aggressive professional outreach campaign and education campaign. We need to have referrals come from physicians, and we need to have them make the referrals appropriately in the time lines that are recommended under protocol.

Thank you.

ASSEMBLYWOMAN HECK: May I respectfully request that the educational pieces you spoke of, including the possibility of doing a VCR, be

given to the members of both Committees, so that we, in turn, can disseminate it within our districts? I think that would be appropriate. I think it is important for us to know what you are doing, so that we, in turn, can spread the word, much along the lines of the American Cancer Society's Tell-A-Friend. It really does grow.

MS. MARSHALL: I want to conclude with just a couple of things. I think that in order to implement the recommendations of the Summit, that we -- meaning all of you and us -- must be the architects of change. We have to make this happen. However, we must learn to work better with the communities by empowering the communities to become stakeholders in their care. This is for the mutual benefit and the common purpose of reducing breast cancer.

We must learn to be comfortable sitting at the same table with each other and discussing our care, whether one is scrubbing a floor or whether one is scrubbing in the operating room. We must not only collaborate, but we should use nurturance, we should use patience, hard work, and, yes, even risks to achieve our goals.

I think when you talk about education and training, we have to put value on that. But change is going to happen, and we must effect change in more positive ways, with community inclusion. Use the communities as our customers, who we work with, our agencies, our legislators, all people who can work with the communities. Also, I think change requires adjustment. We need to really walk the walk and talk the talk for the people we are dealing with, and we need to do our own set of health promotion. We need to move from risk focus to capacity focus. We need to move from isolation and

dependence to interdependence. We need to create and move from access to access within. We need to stop labeling. I think that isolation can stem from various resources, cultural issues such as language, to the extent that people do not know what services are available, alienation due to economic differences and rugged individualization.

So I think we must begin to see people or families as unique and powerful, making all the difference. No longer just clients, but human beings who look to us to join with them in creating the future that they want.

You know, Janet Reno said that the biggest challenge in communities is going to be to cut across the lines of diversity and the lines of disciplines in order to bring people together to develop plans that address the lives of families as a whole. I say that having come from working in a community, that when we do these kinds of strategies, we have to look at the kinds of communities we are dealing with. They might have to be done in the evening. They might have to be done on Saturdays. They might have to be done on Sundays after church. They might have to be done at barber shops and beauty parlors, not to be caught with using the same people as our leaders within the black community, because often what happens is that they are not viewed as the leaders as are the people who have been in the trenches. They might get as much response as you, but often, remember, people respond to people who look like them.

I think when we talk about access and we talk about this report and we talk about early identification and what the action plan should be, often we forget those kinds of remarks and we talk about research, and everyone really is concerned about data, and that has to be data driven -- and

I do support that -- but we really need to include the community as the decision makers and the stakeholders sitting at the table.

I thank you.

ASSEMBLYWOMAN HECK: Thank you very much.

Scott, I think it would be appropriate to mention that Charlotte and I reached out to Commissioner Fishman on jointly putting together a brochure, meaning both of our Committees and our staffers, along with the Department of Health, following your recommendations through the Summit, and putting together a public awareness program and outreach. The Commissioner has agreed to work with us on that. So, along with your group, we will be sitting at the table, in a bipartisan way, putting this together, so that we have a vehicle such as the Help Yourself Be Healthy Guide that we did last year, which is still being moved around the entire State. It's wonderful.

MR. ALLOCCO: Great.

ASSEMBLYWOMAN HECK: So Charlotte and I are very appreciative, on behalf of our Committees, that the Department of Health has agreed to take on that challenge.

MR. ALLOCCO: Well, thank you again for giving us an opportunity to testify. My apologies for not having copies of the testimony, but I will certainly send it out as soon as I get back to the office.

ASSEMBLYWOMAN HECK: I think Assemblyman Jones has a question.

ASSEMBLYMAN JONES: Thank you, Madam Chair.

Through you, Madam Chair, I appreciate the information that you both shared with us -- Ms. Marshall and Ms. Wood. Ms. Marshall, I think you

could not have hit the issue in a more specific manner in terms of, you know, how we begin to communicate with specific communities. Certainly people who share a common bond, who share a common resemblance, are going to be comfortable with and react more readily-- Certainly, we talk in partisan terms here -- bipartisan terms -- but I think we have to be multiracial and multiethnic when we begin to try to talk about how we communicate these very, very serious and sensitive issues. I am glad you touched on that point.

Through you, Madam Chair, Ms. Wood, you talked about the \$2 million grant that was issued by the CDC. You mentioned that that grant serves in various ways, you know, that it was spread out among 12 counties, with 3 counties to be added. You mentioned something that was pretty interesting to me in terms of outreach with respect to mammogram testing -- the mobile mammogram, I believe.

MS. ANDRIOT-WOOD: Mobile mammography.

ASSEMBLYMAN JONES: Mobile mammography. You said it was operational in half of the counties. What counties is this operational in?

MS. ANDRIOT-WOOD: Which counties for the mobile mammography?

ASSEMBLYMAN JONES: Right.

MS. ANDRIOT-WOOD: Middlesex, Essex, wait a minute.
(witness searches through her papers)

ASSEMBLYMAN JONES: You can get it to us if you can't find it.

You said the concentration was in senior centers, senior housing complexes. How does that actually work? Is there like a mobile unit, like a giant van?

MS. ANDRIOT-WOOD: Usually, it is a large van which goes out. There are different contractors for this service. In other words, it is not one van in one place. There are mobile contractors which can either move it through a van situation or there are actually mobile mammography units, which means that they can physically take it from a vehicle and put it into another facility to use for a day, and then return it. In other words, it is not necessarily a van that is actually providing-- You are not going into a van necessarily.

ASSEMBLYMAN JONES: Okay.

MS. MARSHALL: You have both kinds, though. I worked with one where they had a nurse practitioner who taught how to do breast self-examination. They would park outside of the particular area and then they would do the mobile mammography also.

ASSEMBLYMAN JONES: How many individuals is this effort actually reaching?

MS. ANDRIOT-WOOD: The effort is expected to reach 4500 during the course of the current year. Thus far, we only have comprehensive data on 500 women. Most of the projects have been implemented in phases. So we started with five and we have continued to gradually increase to where we now have twelve fully operational. There are some that have started as late as September 1. So we do not have comprehensive data on their screening projects yet.

ASSEMBLYMAN JONES: Now, the 4500 women that you made mention of, that would only be the target number that the \$2 million plus other things would be able to service?

MS. ANDRIOT-WOOD: That is correct.

ASSEMBLYMAN JONES: What would you anticipate, you know, the true number to be served to be and the total cost attached to that?

MS. ANDRIOT-WOOD: The total need? Is that what you are referring to?

ASSEMBLYMAN JONES: Yes.

MS. ANDRIOT-WOOD: There are numbers with regard to the number of women over the age of 50 -- which I also have.

MS. MARSHALL: I would say this to you while she is getting the numbers: That 4500 will be difficult to reach if it is the targeted community or the African-American community. Having come from a hospital where we went to the minority communities and tried knocking on doors to get people to come out to have the mammography, the difficulty is going to be behavioral in nature and teaching our communities that they must do this for their care. It is very, very difficult and time consuming.

While she is looking for that, I just want to say that I have been there. I have done that. I know how difficult it is. You just have to keep going back, going back and knocking on doors, and practically dragging people outside.

ASSEMBLYMAN JONES: Is that something that you would like to forward?

MS. ANDRIOT-WOOD: We could do that, yes.

ASSEMBLYMAN JONES: Okay.

Lastly, through the Chair, you mentioned the whole public education issue. I am sort of bent on this issue of awareness.

MS. MARSHALL: Right.

ASSEMBLYMAN JONES: We have heard testimony today, very compelling testimony with respect to an employment situation which was rather disturbing. But I believe awareness begins -- is the fundamental first step to begin to address these inconsistencies in our system. You know, *Self* magazine, some time ago, did a promotion to bring this awareness to men.

MS. MARSHALL: Right.

ASSEMBLYMAN JONES: I think that is a fundamental problem--

MS. MARSHALL: Right.

ASSEMBLYMAN JONES: --to men, on the impact of breast cancer on a woman.

MS. MARSHALL: Right.

ASSEMBLYMAN JONES: I would be curious to know, from an awareness standpoint, would your material be focused on that angle, for men to begin to understand this impact?

MS. MARSHALL: There are all kinds of material out there. I certainly have a lot of respect for the American Cancer Society and have worked and volunteered for them. Now that they have ethnically and culturally sensitive literature, they would stand on their heads, really, to get into the community to do what must be done.

I never have a problem with even low literacy literature. There is so much that is available. So there really have been true pathfinders within all of the associations and with our physicians in cancer research working really to help with this problem.

ASSEMBLYMAN JONES: Thank you.

Thank you, Madam Chair.

ASSEMBLYWOMAN HECK: You will send us copies of what you discussed?

MS. MARSHALL: Yes.

DR. WALLNER: Thank you. I am--

ASSEMBLYWOMAN HECK: I'm sorry, Doctor. Go right ahead.

DR. WALLNER: Go ahead. You're the Chair.

ASSEMBLYWOMAN HECK: Did you have someone else you were going to introduce?

DR. WALLNER: I was going to conclude.

ASSEMBLYWOMAN HECK: Oh, you want to close, Dr. Wallner? I thought you were going to be part of our panel. Go ahead.

DR. WALLNER: I beg your indulgence. I realize the hour is late and some of the speakers have gone a little bit over their allotted time. I would like to summarize in just two minutes with perhaps how you can partner with us in dealing with these issues, because we have talked about a lot of subjects this afternoon.

First, to take about 15 seconds of those 2 minutes, I would like to dispel two myths: We have talked a lot about cost. We keep hearing the issue cost, cost of mammography, cost of treatment, cost of clinical trials. I would

like to point out one cost that was never discussed, and that is the cost of failing to cure breast cancer. It is cheaper, monetarily, forgetting the emotional issues, the family issues, the suffering issues. Financially, it is cheaper to diagnose early and cure a case of breast cancer than it is to fail to cure that patient. So if we are looking purely and simply at cost, this is good financial policy, to cure this disease.

The second myth I would like to dispel is that of research. Very often, research is discussed in sort of a warm, fuzzy fashion: "Isn't it nice to support research. We think it is a good, well-spirited thing to do." I need only point to Southern California, Eastern Massachusetts, the research triangle of North Carolina. Partnerships between the public and the private sectors to support and generate and expedite good research is good business and good public policy. So I would try to dispel those two myths.

How can you partner with us? There are some general themes that you have heard this afternoon, "Well, we need your help." Some of them relate to legislation. Clearly, that is within your bailiwick. Some of them relate to your job as oversight. As Assemblyman Jones suggested, we need better protection for job security and prevention of job discrimination, not only for women with breast cancer -- a lot of these women are single parents, sole support for their children -- but we also need it for all cancer victims. We need to ensure the leadership of the Department of Health and Senior Services in access to mammography for all women. Women with Medicare and Medicaid typically have some level of coverage for mammography. We really need to focus on the uninsured and, in the Medicaid population, getting women out.

It is not always the issue of coverage. We need to get them to have the mammograms that may be available to them.

We need your assistance in promotion of access and utilization and reimbursement for clinical trials. We need a guaranteed place of research funding support, ideally, stable and increased. You have to understand that the checkoff for all of its benefit is a high risk. It can fluctuate in any given year, and we have statutory inability to give out funds until we have them in hand. So we will not be able to give out 1997 funds until 1998, effectively. We will be able to use the discretionary funds that the Governor allocated to us now, so there is a year lag in our ability to use those funds and, depending on interest, and depending on other checkoffs which might be developed, those funds will fluctuate. So you need a stable funding base.

We need your help to stimulate physician education, public education. We need your help in continued, possibly increased, but certainly continued stable support for the State Cancer Registry. What we have seen in years of downswings in the budget are downswings in support. It is very difficult to continue research with that kind of swinging support.

We need an increase in dynamic communication with the tumor registry and access to timely data. We need to reduce duplicative activity. There are too many agencies doing similar functions. We need to begin to reduce those.

We also need, with your assistance, to expedite the ability of the Department of Health and Senior Services to partner with other public and private organizations. The Department of Health is an important player in

this regard, but there are lots of obstacles to their partnering with other organizations.

With some of these things, which you can accomplish rather easily without significant outlays of funds necessarily, we look forward to your working with us and with us working with you to improve our battle against breast cancer.

Thank you very much.

ASSEMBLYWOMAN HECK: Thank you, Doctor.

The next three people we are going to call up are: Dr. Caroline Glicksman, Plastic and Reconstructive Specialist; Dr. Barbara Rabinowitz, a member of the New Jersey State Commission on Cancer Research; and then Judi Klein.

C A R O L I N E A. G L I C K S M A N, M.D.: My name is Dr. Caroline Glicksman. I am a plastic and reconstructive surgeon. I practice in Monmouth and Ocean Counties.

Today, both physicians and women diagnosed with breast cancer have an additional challenge -- insurance companies denial or limitations of coverage for postmastectomy breast reconstruction.

Currently, only 13 states have mandated insurance company coverage of breast reconstruction surgery, and, fortunately, New Jersey is one of these. Of these states, Maine is the only state, thus far, that mandates both postmastectomy reconstruction and reconstruction of the opposite breast to produce a symmetrical appearance.

Today, when we can reconstruct a credible breast, many insurance companies rule breast reconstruction cosmetic or not medically necessary, or

deny coverage of symmetry operations to make the breasts resemble each other as closely as possible.

Like all plastic and reconstructive surgery, breast reconstruction has two major goals: reconstruction of the missing body part and a good cosmetic result. Fighting for coverage of breast reconstruction and symmetry procedures is both fatiguing and demoralizing.

We all know that early detection and treatment is the only way to fight breast cancer, and the fear of losing a breast and becoming disfigured is a leading reason why many women do not participate in early breast cancer detection programs.

New Jersey has passed legislation mandating breast reconstruction coverage by health insurance companies. We must continue to move forward, to pass legislation mandating coverage of surgery on the opposite breast to create a symmetric appearance. For many women, having two symmetrical, natural-looking breasts is essential to a feeling of well-being, a sense of wholeness, and the ability to live a happy and productive life.

Members of the Assembly Health Committee and the Assembly Policy and Regulatory Oversight Committee, as a plastic and reconstructive surgeon and as a woman, I have seen the female breast become a target for insurance companies that seek to trim insurance benefits and increase their shareholders' profits. You need to be the conscience of the HMOs and health insurance companies, and continue to mandate coverage for all postmastectomy breast reconstruction surgery.

ASSEMBLYWOMAN HECK: Thank you very much.

That is a very important point. It does result in death when they do not go for tests or do not have the surgery at all.

ASSEMBLYWOMAN VANDERVALK: May I ask you, is there any easy way to figure out who covers what? I mean, you know, with all the different insurers out there, do they all handle it differently, or do you find that there is a pattern?

DR. GLICKSMAN: They all handle it individually. I know it is case by case. My office staff battles continuously for coverage. You know, we do have the laws of the initial reconstructive procedures covered. There are multiple stages involved in breast reconstruction. A breast isn't really a breast without a nipple on it. A lot of insurance companies say, "That's cosmetic." Well, tell that to the woman. It is not a breast until it is completely reconstructed. The biggest problem is surgery on the opposite breast. We need to make the two breasts resemble each other, or it is of little value to that woman.

In addition to the breast cancer problem and the reconstruction problem, we have no mandates on reconstructive surgery for congenital malformations of the breast. My patients are 18, 19 years old, missing a breast. That is considered cosmetic? We have to fight, go to the Insurance Commission of the State, and breast reduction surgery is being limited more so and more so as to what they will allow or consider eligible. It is clearly medically necessary in many cases.

ASSEMBLYWOMAN VANDERVALK: Thank you. Thank you very much.

ASSEMBLYWOMAN HECK: We will look into that.

Thank you.

Barbara Rabinowitz.

BARBARA RABINOWITZ, Ph.D.: Distinguished panel: Dr. David Sloan, who is the Medical Director of the Cancer Center at Monmouth Medical Center, and myself, as Administrative Director, thank you for the opportunity to present our thoughts to you.

As a member institution of the St. Barnabas health care system, we are very interested in a statewide action plan and have been happy to be a part of the professional group that came together to bring forth recommendations.

The Summit report showcases the goals, objectives, and action steps for each of the issues described by Dr. Wallner and others. These issues are laid out in exquisite detail in the report of the Summit. There are two issues among those represented in the robust report on which we wish to focus our comments today, one of which is global, perhaps more understated, and an intuitively understood intention of the report, and the latter more specific.

With regard to the global issue, we wish to reinforce that the report of the Breast Cancer Summit calls upon all of us in the State of New Jersey to function in a way that focuses far more on the collaborative, and far less on the competitive. To bring the stated goals and objectives to fruition, the report calls upon us to foster a participatory process, each in our own way and reaching across multiple milieus in any way possible.

To accomplish the goals and objectives we all have to be willing to communicate with each other and to make commitments to understanding the unique roles that each of us can play, whether researcher, clinician,

psychosocial specialist, legislator, policy expert, survivor, or other. There is a role for each of us, and we do best when we attend to the multiplicity.

In addition, the report charges us all, especially in the current health care environment, to be creative in seeking opportunities to move these processes forward. We have to push the envelope. We are each expected to and must be willing to act as colleagues to seek out opportunities, to be part of any appropriate initiatives, and to be proactive in finding the good fit for our involvement. That responsibility belongs to each and every one of us. If we take each of these responsibilities to heart in this fashion, the report of the Breast Cancer Summit will surely become a document that lives by its accomplishments on behalf of the women of New Jersey.

To move to the issue of specific nature that we wish to address: This relates to a necessity in the provision of breast cancer services, as noted specifically in the chapter on therapeutics. We quote now from that chapter:

“National standards of care now include the right of patients to be partners in their care in a multidisciplinary, comprehensive setting in which consultation, collaboration, and knowledge of new treatment modalities is the norm.”

The therapeutics chapter shows five objectives to support the goal of improving five-year survival rates for all breast cancer patients in New Jersey to at least 5 percent better than national averages. One of those stated objectives is: “To develop standards for comprehensive, multidisciplinary breast cancer care and encourage all institutions to adopt a collaborative, multifaceted approach to the disease.”

The benefits of care in comprehensive settings have been well reported in the past in a variety of settings and with a variety of disease processes. Comprehensive breast centers which make good use of the multidisciplinary team model have emerged in many care settings around the country. These programs bring together: breast, general, or oncology surgeons, medical and radiation oncologists, plastic surgeons, nurses, psychosocial specialists, pathologists, radiologists, dieticians, and others to serve women on a continuum from screening and diagnosis through all treatments and on to lifelong survival.

Multidisciplinary teams working in such close collaboration decrease fragmentation, and that is important for women. Such settings also may even, and also often do, enhance practice as each specialist is exposed to each other's disciplines, specific research, and treatment standards at the regular multidisciplinary treatment planning meetings that are a stable finding at comprehensive breast centers.

In addition, one recent project found women treated in comprehensive breast center settings to perceive more professional support than those treated in nonbreast center settings. Given the oft studied and reported value of support for women with breast cancer, this proves a preliminary finding of more than incidental importance. Breast cancer professionals have sometimes been accused of talking the talk and not really walking the walk of multidisciplinary, comprehensive services.

We believe that although not all institutions may feel prepared to embrace the full comprehensive breast center model of our Jacqueline M. Wilentz Comprehensive Breast Center at Monmouth, it is, nevertheless,

imperative that we have the expectation that professionals work closely in every health care setting to adopt this collaborative, multifaceted approach that is championed in the Summit report.

We believe, further, that those of us committed to this objective must come together to describe and to speak for the standards of comprehensive, multidisciplinary care, whether as a legislator, using the visibility that is inherent in your position to increase the awareness of your constituents about such comprehensive care, or as health care providers, survivor advocates, or others. In helping to further define and then promote this standard of care, we all become part of the team that fosters the availability of only the very best of breast care services.

It is, after all, our privilege to do so. It must be our responsibility to do so, and it should be our honor to do so as well.

I thank you for the opportunity to speak with you.

ASSEMBLYWOMAN HECK: Thank you very much.

Are there any questions for the Doctor? (no response)

Do you have a copy of your statement to leave with us?

DR. RABINOWITZ: I will fax it in the morning.

ASSEMBLYWOMAN HECK: Terrific. Thank you very much.

We appreciate that.

Judi Klein, New Jersey Breast Cancer Coalition.

JUDI M. KLEIN: Hi. My name is Judi Klein, and I am the President of the New Jersey Breast Cancer Coalition. I tell you that because I want you to understand that I am a full-time breast cancer activist.

ASSEMBLYWOMAN VANDERVALK: I'm sorry, we are having a little bit of difficulty hearing you. Maybe if you pulled the microphone a little closer--

MS. KLEIN: (witness complies) Okay?

ASSEMBLYWOMAN HECK: Yes, it is on now.

MS. KLEIN: I am a full-time breast cancer advocate. That is what I do. I want to make sure that we don't sidestep the issue around here today. As much as I am an advocate, Ms. Bates' issue is not the issue today. That is something that needs to be dealt with, with all kinds of health issues. Women need to be in a more controlling environment where they have some say over what happens in their lives and in their jobs.

Assemblyman Jones' question about finance and mammography is not why we are here today, because those issues are also being taken care of. They are being looked into. They are being dealt with, with the CDC's \$2 million program we have in this State. They are being looked into by the American Cancer Society, which has a major outreach program in this State.

What we are here for is to figure out what we can use this report -- how we can use it to eradicate this disease. New Jersey does not need to be at the top of the list when it comes to women dying of this disease, nor does it have to be at the top of the list of men who have this disease.

Our primary need here is to eradicate the disease, and that can only be done with research money. All of these awareness programs of early detection-- Early detection does not eliminate breast cancer. As far as the FDA reform, I am also involved in a program with that. I would be happy to work with you on that.

Rose knows that I have been very involved in anything that relates to research in the State of New Jersey. The Genetic Privacy Act has not been passed. It is pending and it should be, and it is up to you people to--

ASSEMBLYWOMAN HECK: It is passed. It has not been signed.

MS. KLEIN: It has not been signed, because it went under conditional veto.

ASSEMBLYWOMAN HECK: Yes.

MS. KLEIN: We need to make sure that it does get signed. We cannot let go of that issue until it is signed. It is the strongest one in the nation, and that is something we need to be proud of in this State. That was done because of you people. We need the Legislature to continue to support the Cancer Registry and to make sure that all of the other information that should be available to researchers in this State is made available.

New Jersey has to take control of New Jersey. We can no longer let people go wandering off to New York, Pennsylvania, or some other state because they think they cannot get what they need here. We need to be able to supply that for them.

What we also need is to look into a new law. Maybe one of the things that you all need to know is that every woman who has had a lumpectomy owes it basically to a woman named Rose Kushner. Rose was so adamant about not losing her breast that she brought it all over the country. What she did was, she created a law that said doctors had to tell you that you could have an option. You have a two-step procedure now. You have your biopsy, and then the doctor has to give you your option.

Maybe what we need now is to look into the possibility that when the doctors give you the options -- their thoughts on your options -- they also give you the clinical trials you might be eligible for. If we mandate that doctors are required to give women the appropriate information, both on when they are due for a mammography-- Let's make some of the physicians responsible for the fact that a woman who is in their care does not know that she is eligible for mammography. It needs to be in their notes that they offer her that prescription every single time. Women need to know that they don't even need a doctor's prescription to go get a mammography.

But we need to make the doctors culpable. We need to mandate that they tell them what they are eligible for and what programs are out there for them, and what research has done for the women who have survived this disease, because every woman who had a lumpectomy did it because of clinical research. Otherwise, everybody would still be getting a radical full mastectomy.

I think we need to look at the way we handle some of these things and how we can go after research dollars in a better way.

Thank you.

ASSEMBLYWOMAN VANDERVALK: Thank you.

ASSEMBLYWOMAN HECK: Thank you.

Are you Mark? (affirmative response from audience) Mark is a survivor.

MARK A. GOLDSTEIN: I accompanied Judi to the table here because -- it is not frivolously said -- we are bosom buddies.

Mesdames Chairpersons, Committee members: Thank you very much for the opportunity to talk a little bit about breast cancer in men. I will limit my remarks to the early detection area, the awareness area, which Assemblyman Jones spoke about earlier.

First, I would like to commend you on the quality of the report. It was certainly an excellent job. I would also like to thank Judi Klein for bringing this hearing to my attention. If it were not for her, I would not have had this opportunity given to me.

I have an assignment for you folks, and this is an easy assignment for you to carry out. At your next visit to your gynecologist or your oncologist or your GP or your surgeon, revisit several of the pamphlets and brochures which discuss breast cancer and see how many of those brochures mention that men may also develop the disease. You will be struck by an all too familiar misconception. It is an error of omission, rather than commission, and that is that men may develop breast cancer.

When next you view a TV program, either whole or in part, on the subject of breast cancer, count the number of times it is mentioned that men may develop breast cancer. Two such examples spring to mind: One of them was a one-hour show on *Larry King Live*, about a week and a half ago, another was on *Nightly News* with Tom Brokaw. Both of the programs talked about breast cancer, but neither program spoke about the fact that men may develop breast cancer, thus perpetuating the mythology again that this is a women's-only disease.

Or pick up some magazines. Pick up a magazine such as AARP's *Modern Maturity*, or the American Cancer Society's *Living Right*, and try to find

mention that men may also develop breast cancer. Even amongst advocacy groups, little is mentioned about men developing the disease. Even in this very, very comprehensive report, only by virtue of the comments made by John Whitman on page 39. There are 4 words in number -- 4 out of 45,000 words devoted to the subject of breast cancer. Only at that point was mention made that men can develop breast cancer, so the mythology, again, is perpetuated.

So amidst the statistics and the advice on prevention, detection, treatment, and support, countless numbers of men and women have the notion reinforced that breast cancer is for women only. Rarely is mention made that men can also develop breast cancer.

And I am one of approximately 1400 men who developed breast cancer. Some 300 or so are fatal each year, not unlike women. We undergo mastectomies; we take chemotherapy, radiation therapy; we take tamoxifen; we develop lymphoedema; and some of us die. Because conventional wisdom says that men are not candidates for breast cancer, many times it is diagnosed in its later stages, and the men have to go through harsher treatments of chemotherapy and radiation therapy.

So my overall objective is to heighten awareness of breast cancer in general, and specifically, the need for expeditious identification of causes and cures to dispel the misconception that breast cancer is for women only, and also to be an example of retaining control over one's lifestyle.

Now, here is my request of the Joint Committee: In the early detection action plan -- which is already written -- but in carrying it out, and in other relevant areas, add the all-important revelation that breast cancer is not for women only. You have heard, from the educational side, about

videotapes being prepared, brochures being prepared, so in outputs from this Committee and from other proceedings, ensure that those four or five words, even if in parenthesis-- Make sure the thought is mentioned that men may also develop the disease. As recommendations to other major breast cancer organizations, to the American Cancer Societies of the world, to hospitals, to other involved organizations -- recommend that they include in their description of breast cancer the fact that men can develop the disease. In written materials and discussions, to the extent that you can influence the content of publications and pamphlets, proceedings and minutes, ensure that those four or five words are put there right next to the overwhelming statistics that would lead you to believe that this is a women's-only disease.

I don't see confrontation. I only want to be complimentary, and I know you want to serve the same role. That is exactly the role you can play by adding that one piece of very important information. Just as I have been given the opportunity -- and I view breast cancer as that, as an opportunity -- you, also, have that opportunity, by virtue of your influence, to spread that word that the disease is not limited to women only.

That is the point I wanted to make, and I thank you for the opportunity.

ASSEMBLYWOMAN HECK: Thank you very much.

That is going to make us look at all the materials to see if and how many times men are mentioned.

MR. GOLDSTEIN: Assemblywoman Heck, that is precisely what my intent is. Look at them and ensure that mention is made that men may also develop the disease. Without that, men will not look at themselves

seriously. I discovered mine through self-examination. I was very lucky. But the macho aspect of the man does not often allow him to look at himself seriously--

ASSEMBLYWOMAN HECK: In that way, yes.

MR. GOLDSTEIN: --unless he believes that something could happen to him.

ASSEMBLYWOMAN HECK: That's true.

MR. GOLDSTEIN: Information is power, knowledge is power. You have an opportunity to increase the power of all people who may be subject to the disease.

ASSEMBLYWOMAN HECK: I can assure you that this Committee is going to be well aware and will promote what you want to happen.

MR. GOLDSTEIN: Thank you very much.

ASSEMBLYWOMAN HECK: You're welcome.

ASSEMBLYWOMAN VANDERVALK: Thank you.

ASSEMBLYMAN JONES: Madam Chair?

ASSEMBLYWOMAN HECK: Oh, I'm sorry. Yes?

ASSEMBLYMAN JONES: If I may, I just want to point this out, because I think you make some very, very cogent points, which I touched on a little earlier. The American Cancer Society does put out a booklet on cancer of the breast in men. It is a booklet that is totally dedicated to, you know, an issue that is obviously not gender specific.

Certainly, we need to see a proliferation of this kind of literature, and that accented more from a media standpoint through the electronic media.

Obviously, it is done through the print media, but there is some specific reference material dedicated to men.

MR. GOLDSTEIN: I'm glad that you have shown me that. Not that I haunt the waiting rooms of doctors' offices and hospitals, but on the occasions when I am there accompanying my wife for a mammogram, or in a doctor's office or a hospital--

ASSEMBLYMAN JONES: Right.

MR. GOLDSTEIN: --I look for the brochure areas, and I have not seen it.

ASSEMBLYMAN JONES: You're absolutely right.

MR. GOLDSTEIN: That is where the information is spread. I picked up a shower card -- something you hang on your shower -- at one of the hospitals just yesterday. On one side, it said, "For Women Only," and that was breast cancer. If you turned it over, it said, "For Men Only." Now, there is prostate cancer and testicular cancer.

ASSEMBLYMAN JONES: Right.

MR. GOLDSTEIN: So you would think that our cancers are below the belly button. But we are candidates for the other, infrequently, by no means at the level that women are exposed to. However, on an individual basis, it is just as tragic for a man to die from breast cancer as it is for a woman to die from breast cancer, especially if it is because of a lack of knowledge.

ASSEMBLYMAN JONES: I agree.

ASSEMBLYWOMAN HECK: We will pass that on to the Medical Society as well.

MR. GOLDSTEIN: Thank you.

ASSEMBLYWOMAN HECK: Pamela Ransom, Women's Environment and Development Organization, in New York City.

Thank you for coming.

P A M E L A R A N S O M, Ph.D.: Thank you for having me.

Once again, thank you for the invitation to appear before this Committee to address important issues on the direction of the State on breast cancer policy.

As was just said, my name is Dr. Pamela Ransom, and I am currently a Project Director with the Women's Environment and Development Organization in New York City, an organization headed by former Congresswoman Bella Abzug.

Our organization has been instrumental in organizing hundreds of nongovernmental organizations and in lobbying for women's positions at the major United Nations' conferences over the last six years, including the Fourth World Women's Conference in China, where we organized 80 nongovernmental organizations and had panels focusing on the issues of breast cancer and the environment.

In addition, we have held public hearings in many cities across the country focusing on the connection between breast and other cancers and the environmental link.

Breast cancer is the most frequently currently diagnosed cancer in women in industrialized countries. Incidence rates and, to some extent, mortality, have increased worldwide by 26 percent just since 1980 alone. The United States leads the world in breast cancer incidence and, as we have heard many times this afternoon, New Jersey has the third, or perhaps the seventh

highest mortality rate in the country. This State has the largest number of Federal Superfund sites in the country and is the fourth largest hazardous waste generator in the nation. Its proliferation of chemical facilities and hazardous dumps should increase the urgency of understanding environmental connections to the health indicator.

I would like to quote Bella Abzug when she said, "Early detection is not prevention." Evidence is growing that the two leading risk factors for breast cancer -- exposure to excessive estrogen and high-fat diets -- may be exacerbated by exposure to environmental chemicals. New evidence is emerging that whole classes of compounds may be capable of mimicking the actions of normal hormones in the body. The evidence that chemicals can function as hormones is abundant and comes from four types of scientific studies: human and animal cell cultures; experimental animal studies, wildlife biology; and human epidemiology.

The link between organic chlorines and breast cancer was strengthened a few years ago at the release of a study by Dr. Mary Wolfe, a chemist from Mt. Sinai School of Medicine, that showed that women with the highest exposures to the organic chlorine pesticide DDT had four times the breast cancer risk as women with the lowest exposure. These findings have been substantiated by several other studies of DDE, a derivative of DDT, and PCBs in tissues of breast cancer patients.

Many scientists now share the view that organic chlorine pesticides are one among a class of substances that have an effect on estrogen, including some plastics, volatile materials and fuel, some pharmaceuticals, and, as I said, some PCBs. The new evidence emerging about harmful effects of substances

previously thought benign is highlighted by experimental studies by Anna Soto at Tufts University, which found unexpected breast (indiscernible) proliferation in laboratory petri dishes traced to chemicals used in the production of the plastic dish, made to make the plastic more flexible.

The new book released over the last few months by Dr. Theo Colburn of the World Wildlife Fund, with an introduction by Vice President Gore entitled *Our Stolen Future*, analyzes much of the evidence, which all of you should read. Regulatory agencies at the Federal level are currently in the process of reviewing strategies based on these findings. A study by Cantor compared death certificates of 59,000 breast cancer victims coded by industry and occupation to a similar group of noncancer deaths, and suggested associations for occupational uses for styrene, several organic solvents, several metal oxides, and acid mists. This is one among many studies that are showing possible relationships between breast cancer and environmental risk factors.

Just to mention a couple that have taken place in New Jersey, there was the 1991 study by Hall, which found a correlation between increased breast cancer risk rates among African-American women employed in chemical-intensive industries in New Jersey and breast cancer mortality, they said. A 1985 study by Retha found an association between increased breast cancer mortality and chemical waste disposal sites. Also, there is evidence from the EPA showing the counties with the highest number of hazardous waste sites and groundwater contamination correlate with deaths from a number of cancers, including breast cancer.

Low environmental risk factors for breast cancer are not conclusively established. The association between cancer and elevated

magnetic field exposure is abundantly present in recent scientific literature. The rise in electric power consumption in this century in industrialized countries is indisputable. Electric power produces magnetic fields and light at night, both of which have been reported to alter penile function and its primary hormone, melatonin.

The evidence of the effect of melatonin on the growth of breast cancer has been experimental in animals and is strong, but the evidence in humans is scant because research is still proceeding. Exploration of this biological mechanism is on the cutting edge of research in breast cancer today. Further scientific investigation, both epidemiological and laboratory, is essential to increase our understanding of why larger and better designed studies continue to point to a relationship between EMF and cancer.

Beyond the laboratory, we face the acute need for congressional leadership in determining interim measures for prudent public education and policy. Even if a small percentage of the 45,000-plus breast cancers diagnosed annually in the United States are related to EMF or other environmental factors, then we face a challenge of staggering proportions to educate and guide women on this issue. The importance of careful consideration of precautionary policies cannot be underscored. We ask that your action plan be revised to include a specific focus on environmental factors influencing breast cancer.

Further, we ask that consideration be given to revision of the tumor registry to collect information on environmental exposure, such as occupational exposure to chemicals and EMF exposures of women diagnosed with breast cancer, tied with an aggressive research effort focused on breast cancer and environment. Scientific and policy specialists with background on

these potential risk factors have volunteered their expertise to assist you in this effort, and they can be reached through our organization.

By the way, in the last couple of months, we have come out with this handbook on environmental leads to breast cancer in New York, New Jersey, and Connecticut. It has a whole range of suggestions or recommendations which perhaps could be considered as you think about these issues.

ASSEMBLYWOMAN HECK: Oh, very good. We would like to have it. Do we have a copy? Yes, we have a copy.

I thank you very much for coming.

DR. RANSOM: Okay. Thank you.

ASSEMBLYWOMAN HECK: Assemblywoman Weinberg?

ASSEMBLYWOMAN WEINBERG: I thank you for coming, too.

I thank Bella Abzug for continuing leadership in this area, also.

Can we get copies of your testimony?

DR. RANSOM: Yes, I will fax it tomorrow.

ASSEMBLYWOMAN WEINBERG: Okay.

Given the suggestion you just made, I would hope that Dr. Gursky could maybe make note of that and give us some comments back about making sure that the tumor registry, as well as the action plan contain some work on the environmental links to breast cancer, which, of course, gives a very logical explanation as to why it seems to be growing in the Northeast.

ASSEMBLYWOMAN HECK: If you could supply one for the Department of Health, we would appreciate it.

DR. RANSOM: Fine, I will.

ASSEMBLYWOMAN HECK: Thank you very much.

Oh, I'm sorry, did you want to ask something?

ASSEMBLYMAN JONES: I'm glad that Dr. Ransom testified today. You know, I hope there will be consideration for those revisions in the report that pertain to the environmental factors. I am glad she talked about the exposure to DDT, given some of the material I had been privy to that specifically talked about the issue of these environmental factors and how they led to potentially increasing the rate of breast cancer. However, due to mammography, there has been a stabilization, but, nonetheless, there has been, obviously, an environmental impact in many, many areas.

I think it is certainly worthy of due consideration and ultimate even revision, and just, you know, consistent follow-up as we move forward with exploring these issues.

Thank you very much, Doctor.

ASSEMBLYWOMAN HECK: Does the Congresswoman stay active in your group?

DR. RANSOM: She is active all over the country and all around our world.

ASSEMBLYWOMAN HECK: Well, you tell her how much we admire her. Convey that to her, please.

DR. RANSOM: I will. Thank you.

ASSEMBLYWOMAN HECK: We will now have Dr. Generosa Grana, from Cooper Hospital, a member of the New Jersey Advisory Group on Breast Cancer Research.

I am so happy to see you again.

GENEROSA GRANA, M.D.: Thank you.

Thank you for allowing me to speak with you today. I know it is late, so I will keep my remarks short.

I come before you as a member of the American Cancer Society Breast Cancer Task Force and the New Jersey Breast Research Advisory Group, but primarily I come before you as a medical oncologist involved in the treatment of breast cancer and in the areas of breast cancer prevention and control.

Despite all that we have heard today, and all of the strides we have made in the treatment of breast cancer, we know very little about the prevention of breast cancer, and we are actually urged by many national advocates not to use the word “prevention,” because we have no preventative options at this point.

I believe the Breast Cancer Summit report and today’s hearing can make a significant impact and really bring us to the forefront of this research and get us to the point where we will be able to make an impact.

I would like to highlight what I feel are three vital areas in this field: The first -- and it has been touched on extensively -- is the need for continued research in the areas of cancer prevention and control. Again, we do not know what causes cancer. We have just heard that environmental factors may be a cause. There is significant research that has focused on genetics. There has been significant research that has focused on reproductive factors and a woman’s own indigenous hormonal history. It is critical that epidemiological studies be fostered in New Jersey so we may gather critical information about breast cancer causation, the interaction of genes,

environment, and reproductive factors. Based on this knowledge, true prevention may become a possibility.

We at Cooper Hospital, in collaboration with the Coriell Institute, have been funded by the National Cancer Institute to be part of a familial breast cancer registry, collecting inheritory information, epidemiologic information, and tumor materials that can then be distributed to researchers nationwide. It is based on that type of model that we can further our research in New Jersey.

The additional funding for the tumor registry, and the additional work that the tumor registry is doing are critical. Again, we need a very up-to-date and very comprehensive tumor registry that will provide us with the materials and the information on which to base our research.

It is also critical that research focusing on drugs that can be used in the prevention of breast cancer be carried out in New Jersey. The current study looking at tamoxifen in the prevention of breast cancer is a national study. It is looking at 16,000 women. Half will get tamoxifen, half will get placebo, and five years from now we may really understand whether this commonly prescribed drug in the treatment of breast cancer can prevent the disease in high-risk women who do not yet have breast cancer.

We live in a State that is rich in pharmaceutical industry conglomerates. It is really important that we work with the pharmaceutical industry to harness some of that and to develop new preventive approaches to breast cancer. It is necessary that they sit at the table with us and that we benefit from their presence in New Jersey in the area of prevention.

The second area I would like to touch on is the issue of broadening access to prevention services and to counseling services. The bill that has recently been passed -- the genetic privacy bill -- is a critical bill for New Jersey, and it is a critical national policy. But right now, as genetic information is unraveling so rapidly, there is no coverage for individuals who need to seek information about their family history and about their genetic risk. Women come to me because their mother, sister, aunt may have died of breast cancer, yet their insurance company does not reimburse for their counseling or for their genetic testing. In many cases, this type of testing is still carried out as part of a research program, but it becomes important that we start to think of the time in which this will become a clinical service, and we need to start working with insurance carriers in our State to make sure that those services are available to all within the State.

Finally, I would like to focus on the need to work with underserved minority populations. Again, this has been touched on extensively, but I think it is of primary importance. Minority populations in New Jersey are increasing, and we have heard extensively about how the burden of breast cancer is disproportionately high on African-American, Hispanic, and underserved women. It has long been recognized that Caucasian women have a relatively good survival rate from breast cancer, an 85 percent five-year survival. African-American women have a 63 percent five-year survival. Although survival is improving for everyone, African-Americans, Hispanic, and other underserved women are not benefiting from these increases in survival, primarily due to late stage of diagnosis, which, again, has been touched on. We need to make sure that mammography and other early detection services

are made available for all groups in our population, not just some who can afford it or who can come forward.

How can we overcome this problem? I believe the keys are to continue and enhance funding for programs targeted to minorities. The Breast and Cervical Program in New Jersey, funded through the CDC, is an important program for our State. It is bringing us up to the level of other states in the area of cancer screening. It is critically important that that program continue and that additional funding be sought from within the State to make these services more widely available.

I believe it is necessary to find funding to develop innovative, grassroots programs hoping to overcome many of the barriers that face minority women. Funding must be developed for educational programs targeted to the very young -- high school girls, college women -- and intermediate-aged women, as well as the older woman who may be living in a retirement community. The dissemination of information to our population is critical, and these are often populations that are difficult to reach where we need to do much more work to get the message across.

I believe it is critical for New Jersey to: Number one, develop the programs, and number two, maintain the level of funding that is required for that dissemination of information to reach all women in our population.

Thank you.

ASSEMBLYWOMAN HECK: Thank you.

ASSEMBLYWOMAN VANDERVALK: Thank you.

ASSEMBLYWOMAN HECK: Do you have any questions for Dr. Grana?

ASSEMBLYMAN JONES: Can we get a copy of her testimony?

DR. GRANA: I will send you one tomorrow.

ASSEMBLYWOMAN HECK: Thank you. Thank you very much.

ASSEMBLYWOMAN VANDERVALK: I just want to say to those who have testified in the last half hour or so that the fact that there is a lack of questioning does not indicate that there is a lack of interest. There has been some really great testimony. We are taking a lot of notes.

ASSEMBLYWOMAN HECK: Anne, who is a survivor, I think. Is Anne still here? (affirmative response from audience) Oh, good, Anne. I just couldn't read the pencil writing, that's all.

A N N E W E N N H O L D: Oh, sorry.

ASSEMBLYWOMAN HECK: Would you please mention your last name?

MS. WENNHOLD: Certainly. My name is Anne Wennhold. I am a breast cancer survivor. I had a mastectomy and chemotherapy in 1989. My experience with breast cancer is one that I haven't heard anyone speak about today, but I would like to share it with you because it is a big, vital part of breast cancer, and one, I think, that we need to be aware of. That is depression.

You were asking a little while ago about how breast cancer affects women. One of the ways it affects women is the fact that they lose a body part, true. Another way it affects women is the sense of loss -- as one of the people in my workshop said -- from innocence. A loss of innocence in the fact that your body does no longer support you, that your mortality rate is much closer than you had thought it would be.

The third way by which depression comes about is in a sense of the loss of control, the loss of control of your environment, as well as your body. I really seriously considered whether or not to move out of New Jersey, because I had heard the statistics and I was really concerned. Is it the soil? Is it the water? Is it the vegetables? Is it the oil? Is it the airplanes overhead? What is it? What can I do to have control over it?

My actual experience was excellent. I went through the operation. I tried to take control in all the best ways. I asked my surgeon to please let me see the lump when she had removed it. I asked her to bring me out of the anesthesia and tell me whether or not she was going to go ahead with the operation, so it would not be a surprise to me when I woke up.

Not long after that, I went back to work with a very good prognosis, but found myself totally not able to cope with my life. I worked, but there was nothing else in my life that was of interest to me, except putting bread and butter on the table. I was alone; I had no family to stimulate me to get out and do other things. The depression took over. As we all know, depression can affect the work world, the economic level, and also very much inhibits healing and good health, which is a part of this cancer problem.

I went to a therapist to help me to deal with the depression. The therapy was not under any category that was recognized. Therefore, we had to fib about the kind of category under which I could get the therapy. He treated me for several months, and found over a period of time that one of the things I liked to do when I was a child was to draw. He suggested that I start drawing. I did that. I took a roll of paper from a physician's examining couch and some felt-tip pens and I started drawing.

The result of that drawing was 150 feet of the feelings I had about cancer, and it ended nine months later. If that doesn't give you some clue about how people feel about having cancer and how it affects their lives, I would invite you to come and see the mural. The Art Center of New Jersey has been, I think, excellent in putting this up as a community awareness situation. I would commend the Hackensack YWCA for having programs that help to develop awareness about this aspect of cancer, and also *The Record Magazine*, which put something about this on the cover of their community issue.

We have talked an awful lot this afternoon, as we always do, about statistics, about the clinical aspects, about the medical aspects, and I am right here to say that I concur wholeheartedly with all of those aspects. But there is an aspect of soul which needs to be addressed. As you know, when people feel good about themselves, they feel healthier and they feel better. Medically speaking, if you feel good about yourself, your endorphin level builds up, and when your endorphin level goes up, your immune system is boosted.

My mission is to help women to find ways to reach within themselves, feel good about themselves, and collaborate with their physicians and anyone else they are working with to deal with this cancer situation. I invite you, as legislators, to back us in any kind of effort we put forth artistically or in other ways to help develop community awareness around the State.

I thank you very much for this opportunity.

ASSEMBLYWOMAN VANDERVALK: Thank you.

I just want to ask you, as an aside, what type-- Do you recall what type of a provider you had who encouraged you to do the artwork?

MS. WENNHOLD: Yes. It was a social worker who was working as a therapist with children.

ASSEMBLYWOMAN VANDERVALK: Thank you.

ASSEMBLYWOMAN HECK: Yes, Assemblywoman?

ASSEMBLYWOMAN WEINBERG: Anne, thank you for sharing your own personal experience. My husband is a cancer survivor. What you just described is the kind of thing, I think, that any cancer victim, no matter what gender or what type, goes through. You described our experience to a *T*, except that he wasn't alone. I thank you for sharing that, because that is a very important aspect of going through this and of the recovery period that one has to go through to bring herself or himself back together.

MS. WENNHOLD: And also to keep from recurrence as much as possible, to help yourself. My surgeon taught me that depression was one of the biggest side effects of cancer, overwhelming any other side effect.

ASSEMBLYWOMAN HECK: And it is debilitating.

MS. WENNHOLD: Exactly.

ASSEMBLYWOMAN HECK: Thank you very much, Anne.

We may call upon you again to speak, Anne, at some future date.

MS. WENNHOLD: Anytime.

ASSEMBLYWOMAN HECK: Dr. Sandra Ruth Pinkerton.

SANDRA RUTH PINKERTON, Ed.D.: Hi, at this late hour.

My name is Dr. Sandra Ruth Pinkerton. I am Cochairperson of the Bergen County Commission on the Status of Women. I am here to represent that group.

The Bergen County Board of Chosen Freeholders observed International Women's Year in 1975 by creating the Advisory Commission on the Status of Women. The Commission is organized under the auspices of the Bergen County Executive, Department of Human Services to:

- *study the needs, capabilities, and concerns of women in Bergen County, and

- *recommend and review programs and plans affecting the status of women in Bergen County, in order to promote the expansion of their rights and available opportunities.

The Commission consists of 22 members. Their high-priority issues include: health care, crimes of violence against women, affordable housing, employment rights and opportunities, child care, sexual harassment, child support collection, care of elderly parents, women in government, education, and legislation affecting women.

The Commission participates in several networking organizations and projects. Through these organizations, the Commission has kept in contact with the concerns of women and has cosponsored several programs.

As I mentioned before, my name is Dr. Sandra Ruth Pinkerton. I am an educator, lecturer, and consultant in various aspects of education, with an emphasis on students and adults with disabilities. I was on the writing team for national education legislation and active in civil rights issues of people with disabilities. I am a member of the Coalition of Women with Disabilities of New Jersey. Presently, I serve on the Fort Lee Board of Education, and am a charter member and Chairperson of the Fort Lee Advisory Board to the Mayor and Council on the Americans with Disabilities Act.

My topic is: Education: The Key to Breast Cancer Prevention and Treatment. Simply defined, to educate means to teach, to cultivate, to enlighten, and, in a rarely used definition, to disseminate. The Commission on the Status of Women is in a position to educate our members who, in turn, can educate others on the need for breast self-examination, clinical breast examinations, and mammography. In order to educate women of all ages, women's groups need to form coalitions and collaborate with each other to establish a comprehensive network system of education, awareness, and dissemination of various informational materials. The network will have to find innovative ways to work with as little funds as possible because, as most of you realize, funding in this area is very small.

First, I would like to begin with some general statements. I happen to live in a senior citizen housing complex, so I am very aware of many of the problems that confront older Americans and the devastation that is caused because of the lack of receiving mammographies and the lack of medical attention.

I also have an interest as an educator. Early detection must really start from high school age females being taught about breast self-examination. In order for this to occur, school nurses and health educators need to be retrained in this whole aspect of breast self-examination. I strongly feel that prevention cannot come unless we start with these very, very young people. Also, we want to educate them through their life span. If we do not start at an early age, it is much harder to get them at 40, 50, 60, whatever the age may be.

I know that doctors are the single referral source, and that very many women avoid taking care of their bodies. Rarely do women go for a

mammography if they are not referred. I thought it was interesting that few of us know you can go for a mammography without a referral. Again, lack of information to the general public. I fear that could become a primary motivator not to seek appropriate care. A lot of times we, as women, perpetuate that fear one to another. “Oh, I found a lump.” “Maybe you better not go,” instead of, “You better go for treatment,” that kind of thing.

On a personal level, I see many specialists with credentials that could appear in *Who's Who*. Again, we have talked very little about personal experience, but I do want to bring this in. After several hospital stays and being under a lot of medical personnel, specialists, I found that no one asked me about whether I received a mammography, although if you look at my age, it was about time to start the baseline, and so forth. It was only my female neurologist who asked me if I had a baseline mammography. I mentioned it to my gynecologist. That was how I received my very first one.

Also, when I saw a gynecologist -- and I don't really understand why this occurred -- the gynecologist did not do a regular breast examination. Again, you would like to say that this is one experience, but I don't know how many other people have experienced this. Considering the number of medical people who interface in my life, it seems very odd that that would occur.

My feeling is, what can be said after a lump is discovered and one has gone through the trauma of having a cancerous breast found. Words are never enough to ease the pain and the reality of an early death.

I don't want to be redundant, but I have several things that I took out of my report and several recommendations I have for future planning with regard to teaching women about breast cancer prevention and treatment.

First of all, school nurses and health educators have to be trained to educate teenagers and their parents about self breast examination and appropriate gynecological care. I know this exists in regular education. I did a training with parents of developmentally disabled women. I asked the parents at that particular course I was teaching how many of them had their adult children with developmental disabilities examined by a gynecologist. Not one hand was raised. So here is a population that had not even begun to get into the system. We were talking about a post-21 population.

Materials for education should not only be written materials, because a large number of people, as you know, are unable to read or write. We also have a large number of non-English-speaking people in America at this time. Media for information about breast self-examination: Clinical breast exams and mammography need to be developed in forms that will reach more people and include videos, public broadcasting, and community networks.

I am also a firm believer that if you really want to reach populations, especially underserved populations, you should go to the supermarket. We all need to eat. I think another place in New Jersey happens to be our malls, since we seem to get national notoriety for that particular phenomenon here.

Women from Asian cultures have to be educated about seeking care and identify reasons why they do not seek appropriate medical care. In speaking with several Asian women, having resided in Fort Lee -- we have a large number there -- the Asian women told me that they did not want to see male physicians. That was a major barrier to them seeking medical treatment. So there has to be a whole lot of awareness of that aspect.

Also, psychosocial aspects appear to be eliminated in the care of breast cancer and the fear that one's female children may be in jeopardy of having breast cancer. My aunt had a total mastectomy. She has two children -- daughters, female children -- in their 20s and 30s. One of her main fears was what was going to happen to them and their breasts.

Again, as I said, having resided in a senior setting, seniors' needs must be met by centers that provide nutrition, recreation, housing, and mobile mammography vans or, as we heard here, even with mammography instruments that can be placed in those buildings. For example, my building has 500-plus people, so I am talking about large populations. Transportation limitations is one reason this population does not seek treatment.

Religious institutions, especially those serving people with meals and providing housing, can be instrumental in getting poor people and minorities to medical care. Women's groups and medical personnel need to establish a connection by coming to the centers that serve the underserved groups. I think we have a perfect population here. We always talk about, "We don't want one or two, we want larger numbers." By going to these centers, we certainly do increase the number of people that we teach.

Again, regional centers, hospitals, and doctors' offices must be barrier free so that individuals with disabilities have access to an appropriate facility and receive the necessary medical treatment. Unfortunately, in the report, I saw no reference to women with disabilities. I feel that was a total omission and one that just compounds the problems that people with disabilities have to deal with.

The watch and wait attitude has to be eliminated. This attitude only further prevents women from seeking help, or even going for a second opinion. Clinical trials, as mentioned, need to include minorities and people with disabilities. Women's groups need to connect with medical personnel and the drug companies that conduct the trials. We have been looking at medical connections, but also feel that as women's groups we need that other connection, too.

ASSEMBLYWOMAN HECK: I just have to interrupt you for one minute. We have about six or seven more speakers. We have to be out of this room in a half hour. So I want you to synopsise what you have to say, or I won't be able to hear every one of those remaining. I do want to make sure that we hear all of the remaining six or seven people.

Go ahead, Dr. Pinkerton.

DR. PINKERTON: Although patient support needs to be more comprehensive and last for a longer period of time, support mechanisms for other family members also have to be instituted. I think cancer affects everyone in a family--

ASSEMBLYWOMAN HECK: Absolutely.

DR. PINKERTON: --and sometimes we actually forget that.

In terms of research, a lot of things were mentioned in terms of money and that New Jersey has a large number of drug companies, and so forth, and what is being done to increase their support of programs in New Jersey.

In summary, a comprehensive network system developed by women's groups can increase education for breast self-examination, clinical

breast examination, and mammography. Our outreach has to include previously unreachable populations, such as the poor, Native Americans, African-Americans, Hispanics, Latinos, Asians, and those with disabilities. Each of us needs to become an advocate and a motivator to enhance all women's attitudes about proper care and treatment.

Thank you for your time. I hope this hearing will be a catalyst toward more meetings with a more visible emphasis upon breast cancer.

ASSEMBLYWOMAN HECK: I am sure it will be.

Dr. Pinkerton, are you going to give us a copy of your statement, or are you going to fax it?

DR. PINKERTON: No, I have a copy for you with me.

ASSEMBLYWOMAN HECK: Oh, good.

Thank you very much.

Denise Adler, Cochair, Psychosocial Advisory Board to the New Jersey Commission on Cancer Research.

D E N I S E A D L E R: Thank you. That is a very long title.

I am, as you said, the Cochairman of the Psychosocial Advisory Board to the New Jersey Commission on Cancer Research. I take this opportunity, and I appreciate the invitation, to raise the issue of psychosocial research and psychosocial issues. I don't think it could have been more clearly drawn today if I had designed all of the testimony myself to highlight the issues that are very critical with regard to psychosocial research in cancer. When we talk about this, we talk about behavioral understanding, and we really have very little of that. It speaks to why women do not get screening, why they do not follow up if they feel there is some kind of a problem, why they are

noncompliant when a treatment is designed for them, what the barriers are to clinical trials, and even on to such issues as quality of life and survivorship.

Although the evidence is clearly not in yet that psychosocial issues can extend life significantly, we certainly do have evidence that it increases the quality of life. But what we need is a considerable amount more research to be able to put us in the right direction. We have a number of programs in the State reaching out to women to encourage them, for example, to have early mammograms, and yet we know that women are not responding in the numbers that we would like. Part of that is that we do not really know what the message is that will be effective.

Cost has been raised as an issue as to why women do not get mammography, and yet our studies show that that is not the major issue. Even among poor, minority women, among women who are at some distance from medical care, cost is still not the major factor. We are only beginning now, through research, to understand what some of those other issues are. But until we have conducted some really significant ongoing research into behavioral issues, into models of belief, we won't really know how to target the message appropriately. So we will put a lot of money into screening programs that will reach some women, but certainly not all women, and not the women we are particularly looking for.

It is very important for us to understand the recovery process. You had speakers today who talked about the importance of psychosocial support. We know that it impacts on their quality of life, and there are certainly studies from a cost perspective that indicate that a higher quality of life and more support do reduce the amount of medical care a woman needs,

or a cancer patient needs going through the process. So it speaks to reducing our overall health care costs, as well as producing more productive citizens.

So it is really critical that we focus on issues of behavioral or psychosocial research in cancer. I would urge you to consider increasing, to the extent that you are able as a Committee, the resources that the New Jersey Commission on Cancer Research is allotted. Fortunately for us in the State of New Jersey, the Commission has been very farsighted and very trendsetting in acknowledging that behavioral or psychosocial issues are really critical to looking at the whole specter of cancer, that we cannot just do basic research, or even clinical research, without understanding why people behave as they do relative to cancer. This is a pretty trendsetting position to take. It has certainly not been the position until very recently, even at the national level.

So their openness to that means additional funding for the Commission, which could translate into additional funding for research into behavioral issues. This is particularly critical when we look at multicultural issues, because even understanding why a particular issue is important for one group of women may not necessarily translate to another group of women. As was just mentioned, there are groups of women who view medical care in very distinct ways. Until we understand that clearly, until we do research to understand why some women are more compliant than other women-- Issues have been raised today relative to why some women are more successful in treatment, and we do not know the extent to which attitude, fighting spirit, and support provided to them are really going to make a difference. This is a very direct assault on the mortality from cancer in our community. I think we need to be very aware of the fact that research has these separate components,

all of which need to be supported. While basic research and clinical research certainly need our attention, we need to be looking at the behavioral component. That does require funding for research.

Our Advisory Group to the Cancer Commission is charged with the mission of promoting psychosocial research in this State. We have been trying to increase the amount of research going on in all of the institutions. I don't have to tell you that with cost cutting today, that is often the first thing that gets cut in any institution's budget -- research and, certainly, psychosocial research, which is often considered sort of the frill.

I would urge you to use your good offices to encourage an attitude in this State which respects and acknowledges the importance of that.

ASSEMBLYWOMAN HECK: I think you are talking to a group that supports--

MS. ADLER: Preaching to the fire, right?

ASSEMBLYWOMAN HECK: No, because we know that behavioral patterns are involved in many, many areas, including child abuse, drug abuse, and domestic violence. So all of those things-- We know the importance.

Again, I think in this particular instance we realize that, too. We appreciate your particular discipline and the need for it, more so today than ever before.

MS. ADLER: I thank you very much.

ASSEMBLYWOMAN HECK: Are there any questions? (no response)

Thank you so much.

Dr. Sanchez? (no response) Don't tell me Dr. Sanchez is not here. I can't believe it.

Mary Joyce Doyle, New Jersey State Federation of Women's Clubs.

See, they were talking about the women's groups, and here you are.

MARY JOYCE DOYLE: I have copies of my testimony. Shall I leave them right here?

ASSEMBLYWOMAN HECK: Yes, please.

Why don't you move your chair down a little? You are going to get the sun in your eyes. (witness complies)

ASSEMBLYWOMAN VANDERVALK: Right there.

MS. DOYLE: I shall be brief, and I shall talk fast.

ASSEMBLYWOMAN HECK: This is her training with the New Jersey Federation of Women's Clubs.

MS. DOYLE: Yes, it is.

I have testified before Senate and Assembly committees before, but always as a librarian.

ASSEMBLYWOMAN HECK: That's right.

MS. DOYLE: This is a new experience now.

My name is Mary Joyce Doyle. I live at 146 Holland Avenue in New Milford, New Jersey. I am the Legislation/Resolutions Chairman for the New Jersey State Federation of Women's Clubs, hereafter referred to as NJSFWC, or the Federation.

NJSFWC, to tell you a little bit about it, is an organization of 19,000-plus women throughout the State. In turn, the Federation is a member of the national General Federation of Women's Clubs, whose headquarters are located in Washington, D.C. and whose members number 10 million worldwide in 40 different countries.

Organized in 1894, NJSFWC is the largest and oldest nondenominational, nonpartisan volunteer service organization of women in New Jersey. Our members work on projects and programs -- and this is why I am here -- to improve our communities, our State, our nation, and our world.

In the latest issue of our *Clubwoman* magazine, the GFWC urged all members to sponsor a Color Me Healthy series of forums, the purpose being to assist women in being better informed to make them more aware of health problems facing women today, and to encourage them to take a proactive role concerning their own health.

There are many facts and statistics that we heard today regarding breast cancer. They are frightening, they are disturbing. The rate of breast cancer in New Jersey, particularly in Bergen County, I feel, is especially puzzling. The fact that more than 80 percent of breast cancers are diagnosed in women who have no family history of cancer, I feel, merits our special attention, for many women believe there is no need for concern, since, "No member of my family ever had cancer." We need to dispel that myth.

We recognize, of course, that the statistics to which we refer reflect the fact that, first of all, women are living longer, and secondly, more women are having regular mammograms.

The designation of October as National Breast Cancer Awareness Month is an excellent means of raising awareness. However, we need to find a way to overcome a basic human trait: the belief that "It can't happen to me." We know, too, that it is not enough to become better informed and take charge of our own bodies. Women must also work to see that there is equity in our health care system, and we have heard a great deal about that -- very important points about that today.

Women are the largest consumers of health care. They are the primary health care providers and caretakers of their families. However, they are supporting a system that does not adequately address their needs. To ensure a healthy, rewarding life for ourselves and those who come after us, we must insist on continued and extensive research. We must be assured that health care reform proposals will serve our needs.

We have heard the words public awareness, empowerment, and research. These are the keys with which we can make a positive difference in the battle against breast cancer. I also represent libraries. When I hear the word education and I hear the word communication and I hear the word awareness, I propose that public libraries particularly have an important role to play here. I would like to see every public library in this State take the wonderful report -- which I have been reading, and which I will read in detail -- and, in conjunction with our women's clubs, sponsor forums using much of the information that is in there, in every single community, because every community has a public library. Have those forums open to provide information and free discussion. I will work on that with the New Jersey

Library Association, and also the New Jersey State Federation of Women's Clubs.

On behalf of the New Jersey State Federation of Women's Clubs, I wish to thank this Committee for holding this joint hearing and certainly for allowing me the opportunity to express my concerns and the concerns of my entire organization, and to pledge to you a promise of support from all our members.

Thank you.

ASSEMBLYWOMAN HECK: And that is major support. Thank you very much.

Pat Hegadorn, I believe, who is from the Bergen County Department of Health. Right?

PATRICIA W. HEGADORN: Yes.

Thank you for honoring my very late request. I have very little to add in the way of information, but I would be remiss if I did not mention to you -- I have spoken to a couple of you individually -- that the Bergen County Department of Health Services is a recipient -- is one of the recipients of a State Cervical and Breast Cancer Screening Grant. I left a pile of these pink flyers at the doorway for you to help yourselves to. One side is in Spanish, one side is in English.

We are targeting women over 50, low income, with no insurance or underinsured, who cannot afford mammographies. One of the reasons I decided that I had a word to say today is because Assemblyman Jones mentioned about mobile units. I want to let you know that here in Bergen County we have gotten an agreement from all of the hospitals that anyone we

find in this screening program, they will be willing to treat whether the person has funds or not. That has to be a very important part of this.

We talk about screening and we talk about case finding. We have to have some way to treat those cases that we find. All of our six hospitals in Bergen County have decided that they will participate in the program. They will do the screening, accept the Medicare reimbursement, and then will treat, regardless of funding, anyone we find. That is something that we were not able-- We just got this grant in September. During this first six months (*sic*) of this grant, we were not able to set this up with a mobile unit. Although I love the idea of a mobile unit bringing the program to the community, it just did not work at the beginning.

We have hired outreach workers. I have hired two part-time Afro-American outreach workers and one Hispanic outreach worker. We got the recommendations through the Hispanic Institute and one of the most active of the black ministers in Bergen County, who gave us referrals. So we are hoping that by going into the community with people who know the groups, that we will be able to access more residents.

What I would ask of you is that-- We would welcome any input that anyone has about constituency groups that might be needy for this kind of service. The telephone number is on the sheet, so if you have questions or if you have groups that you would like us to access, or if you have any ideas about how to access particular groups, please feel free to call. I would love to get that information.

Thank you.

ASSEMBLYWOMAN HECK: Thank you very much.

ASSEMBLYWOMAN WEINBERG: Rose, a quick question.

ASSEMBLYWOMAN HECK: Oh, I'm sorry. Go ahead.

ASSEMBLYWOMAN WEINBERG: A quick question, Pat.

MS. HEGADORN: Sure.

ASSEMBLYWOMAN WEINBERG: Because I would like to help get this information out. Do people need to produce some kind of proof to qualify? Do they have to produce financial information?

MS. HEGADORN: We are taking it on trust, at this point. We are asking their income, and we are asking that they tell us what their insurance is. We don't have a staff of social service workers who are able to review income tax reports and that kind of thing, so at this point in time, we are asking people what their income is, and letting them know that, "You know, if you tell a lie, somebody else doesn't get it if you can afford it."

ASSEMBLYWOMAN WEINBERG: One other quick question, if I may: Are you using existing linkups like the Social Service Federation in Englewood, which already has outreach into the minority and Hispanic communities?

MS. HEGADORN: Yes. Some of the first people we accessed were Encore, through the Y, and the American Cancer Association. Encore, in particular, was very happy to hook up, for the simple reason that they had people like that identified already who did not have the resources for mammography.

ASSEMBLYWOMAN WEINBERG: Well, I will talk to you at some future time.

MS. HEGADORN: Yes. As you know, the county has been involved in the community assessment process for the last two years. We formed a coalition of health care providers and community service agencies, many of which have indicated a willingness to help and participate.

ASSEMBLYWOMAN WEINBERG: Great.

ASSEMBLYWOMAN HECK: Dee Waddington. Dee is with Encore Plus, YWCA of Bergen County.

D E E W A D D I N G T O N: Doesn't it seem appropriate that I would follow Pat?

MS. HEGADORN: Yes.

ASSEMBLYWOMAN HECK: It is. Did you plan it that way?

MS. WADDINGTON: No, but thank you very much for allowing me to speak. I know we have run overtime. I can't believe that you are still sitting there so wide awake.

I represent Encore Plus. It is a program of the YWCA of Bergen County. It is a community outreach program. We are dedicated to educating women on the importance of early detection. We provide educational seminars. I think what we have that is different is that we provide transportation. We schedule appointments, we accompany the women, and we provide the transportation.

I am so thrilled to know that six hospitals will be participating, because we have had a problem with our mobile units. They will only come out if you have 30 women to be screened. They do not take Medicaid. They will accept Medicare. So there is a problem. There are only three in Bergen County that we can use, so this is really good news.

I think our main concern is that this funding that is available to these six hospitals start immediately. We can get the women. We have funding for transportation. Most of the women in our targeted population are the medically underserved, women of color, underinsured, uninsured. It is so important. If we had this money to get the money there, but they cannot afford a mammogram or a Pap test, you know, where can we go?

So my request is that this start ASAP and that the screenings be in the morning, the afternoon, the evening. I loved it when someone said, "On the weekends," because there are women who are in the workforce, there are women with children who are at home who have to wait until there is someone who can watch their children, and it can be at night or on the weekends.

Again, thank you. I appreciate your giving me this opportunity. I look forward to working with you.

ASSEMBLYWOMAN WEINBERG: Great.

ASSEMBLYWOMAN HECK: Thank you very much. We appreciate it.

ASSEMBLYWOMAN VANDERVALK: I have a question. I guess it is probably not directed at you, but to the six hospitals that agreed to cooperate and provide the services.

MS. WADDINGTON: Yes?

ASSEMBLYWOMAN VANDERVALK: I thought when you explained it they were providing the services for the surgery or the treatment after the fact, or were you talking about the mammography itself?

MS. HEGADORN: (speaking from audience) The grant will pay for mammography--

HEARING REPORTER: Madam Chairman, would you please ask Ms. Hegadorn to come up to the microphone?

ASSEMBLYWOMAN HECK: Yes. Would you please come up?

MS. HEGADORN: The grant will reimburse for a mammography, a cervical screening, and certain diagnostic tests. They will not reimburse for treatment. So we could find the people, we had to have a mechanism in place to make sure that anyone we found had access to treatment.

ASSEMBLYWOMAN VANDERVALK: But I just want to understand correctly. What you were saying was that the hospitals have volunteered their services for the treatment.

MS. HEGADORN: Yes.

ASSEMBLYWOMAN VANDERVALK: That is what I thought you said.

MS. HEGADORN: They will get Medicare reimbursement -- that level of reimbursement for the screening, but if they find someone who is positive, they have agreed to treat them.

ASSEMBLYWOMAN VANDERVALK: Thank you.

MS. WADDINGTON: I just want to add one thing: I really urge you to have women who are covered by Medicare to get annual screenings -- they have that covered -- and not every other year.

ASSEMBLYWOMAN HECK: Oh, absolutely. That should be in the booklet that we are going to put out through the Department of Health.

MS. WADDINGTON: Okay. Thank you.

ASSEMBLYWOMAN HECK: Mike Guarino will be our final speaker, I think.

I do have to mention that Carol Vasile, from the Division on Women, did submit testimony, and has actually supported everything we are doing. Particularly, they are concerned about initiatives for women who are underinsured and those working poor who are not insured -- which we talked about before. We will include that testimony in the transcript. Do we all have a copy of that? (affirmative responses)

Also, I have to announce that we received a statement from the County Executive of Bergen County, Pat Schuber. We will have copies of that made and distributed to our membership.

Michael?

MICHAEL GUARINO: Thank you. Thank you for making me the last one. He who is last shall be first. I appreciate that.

You are probably wondering why is a male giving testimony at a breast cancer program. Well, I used to be the County Health Director, Bergen County. I retired seven years ago, but my interests are still in public health practice and the environment.

I want to give you a little history: In 1980, we implemented a Cancer Detection Program for women at Bergen County Hospital. In 1986, we implemented mammography. It took me six years, and I was only able to implement it after I became part of the hospital Board. In 1988, our Program won a national award. In 1990, the Bergen County Cancer Society gave us an award as well. That is just a little background, because my interest in cancer goes back a long time, even when I was at Columbia going for my MPH.

My real concern is, we have legislation that was passed and approved by the Governor that is called Public Health Law 1993, Chapter 327.

It was approved on December 12, 1993. It is Dr. Lauria's bill, Don Lauria, who happens to be the Chairperson for the Department of Preventive Medicine and Community Health at the Medical School in Newark.

Now, we have this bill, but the bill has not been implemented. I called Trenton to find out what has happened.

ASSEMBLYWOMAN HECK: Do you have your testimony in writing, Mike?

MR. GUARINO: No, I really don't, but I have another few minutes.

ASSEMBLYWOMAN HECK: Michael, that point, the point you are making now that you want us to look into, put it in writing so we can follow up and give you an answer.

MR. GUARINO: Okay.

The only reason it has not been implemented -- I mean, it has been signed by the Governor -- is because they have to have an advisory group, one person appointed by the Governor, one appointed by the Senate President, and--

ASSEMBLYWOMAN HECK: All I am asking you to do is give it to us and we will make sure that we look into it right away.

MR. GUARINO: It is important, because it includes several screening programs. Mammography and Pap testing are two of them.

ASSEMBLYWOMAN HECK: Okay.

MR. GUARINO: It has been around for three years.

I will send you a letter?

ASSEMBLYWOMAN HECK: Yes, please.

MR. GUARINO: I will.

ASSEMBLYWOMAN HECK: All right.

MR. GUARINO: I hope you can get better information than I could.

ASSEMBLYWOMAN HECK: We'll get a response. These Committees are very good. We get responses.

ASSEMBLYWOMAN VANDERVALK: Go ahead, Assemblywoman Weinberg.

ASSEMBLYWOMAN WEINBERG: Charlotte, you probably remember. I forgot about that until just now. We took testimony on that in the Health Committee and it set up the protocols on how often you are supposed to have mammography, cervical screening, and so on. I think that came before our Committee in 1993.

MR. GUARINO: Kelly introduced it.

ASSEMBLYWOMAN HECK: Jack.

ASSEMBLYWOMAN WEINBERG: Assemblyman Jack Kelly, yes.

MR. GUARINO: Jack Kelly introduced it.

ASSEMBLYWOMAN WEINBERG: So we should look into--

ASSEMBLYWOMAN HECK: We will look into it, and we will move it.

ASSEMBLYWOMAN VANDERVALK: We'll do a follow-up.

ASSEMBLYWOMAN HECK: We'll move it.

MR. GUARINO: There is a whole list of screening procedures that an insurance company has to offer.

ASSEMBLYWOMAN WEINBERG: Right.

ASSEMBLYWOMAN HECK: Just so you know, we received a statement from Congresswoman Marge Roukema, who could not be with us today. She makes mention of the NCI proposing a special allocation for new research in cancer genetics and related fields. I think I will ask that a copy be made, and also give it to Ann Marie Hill, so she can see it, because it will be of interest to you, Ann Marie. We have to follow up on that now.

I am so grateful. I cannot believe how many people showed up to testify on this. I know Charlotte and I thought this would be a good idea.

ASSEMBLYWOMAN VANDERVALK: We said 1:00 to 4:00.

ASSEMBLYWOMAN HECK: Yes.

ASSEMBLYWOMAN WEINBERG: You're only two hours over.

ASSEMBLYWOMAN HECK: We know that people have to reset this room now. So thank you so very, very much. You will hear a follow-up report on what we are doing.

Thank you again. It has been wonderful.

(HEARING CONCLUDED)