BREAST AND CERVICAL CANCER TREATMENT ACT TESTIMONY
SENATOR BARBARA A. MIKULSKI
JULY 27, 1999

Thank you, Senator Chafee, for holding this important hearing and for inviting me to testify today. I'm happy to join you, Senator Snowe, and Senator Moynihan in sponsoring the Breast and Cervical Cancer Treatment Act. I also want to thank Senator Rockefeller for his support and for being an original cosponsor of this bill.

I'm here today to address the urgent need for this bill that provides coverage for breast and cervical cancer treatment to eligible women who were diagnosed with these cancers through the National Breast and Cervical Cancer Early Detection Program at CDC. This is a bill whose time has come. Breast and cervical cancer treatment is not a partisan issue. It's not a women's issue. It affects mothers, sisters, and daughters, and their fathers, husbands, and children. In short, it affects families. That's why I'm glad to be working with my colleagues in a bipartisan effort to address this pressing public health need.

In addition to prevention, science tells us that the fight against breast cancer has two key steps: early detection and early treatment. That's why in 1990, I was proud to be the chief Senate sponsor of the Breast and Cervical Cancer Mortality Prevention Act which created the National Breast and Cervical Cancer Early Detection Program at the CDC. Since its inception, the CDC screening program has provided 950,000 mammograms and one million Pap tests to more than 1.3 million women. Among the women screened, over 5,000 cases of breast cancer and over 400 cases of invasive cervical cancer have been diagnosed.

Now as we prepare to enter the 21st century, it is time for us to finish what we started. It's time to guarantee treatment services for breast and cervical cancer for women who are screened through this program. We made the down payment in 1990, but it's time for the final payment.

We began the screening program to detect breast and cervical cancer in low income, uninsured, and underinsured women. Screening without any

federal follow-up to ensure treatment is a heart-breaking irony. It is time to do the right thing. Right now, the CDC screening program does not pay for breast and cervical cancer treatment services, but it does require participating states to provide treatment services.

A study of the program done for the CDC showed that initial treatment was eventually found for almost all of the women screened, however the study doesn't monitor quality, timeliness, or continuity of treatment. While states and localities have been creative in finding treatment services for these women, the reality is that the system is overloaded. State efforts to obtain treatment services are short-term, labor-intensive solutions that divert resources away from screening activities.

Women screened through the CDC program have a hard enough time getting screened, let alone getting treatment -- they have no health care insurance coverage or are underinsured. One woman in Massachusetts reported that she cashed in her life insurance policy to cover her treatment costs. These women depend on staff and volunteer time to find free or more affordable treatment; they depend on the generosity of doctors, nurses, hospitals, and clinics who provide them with free or reduced-cost treatment. In the end, thousands of people who run local screening programs are spending countless hours finding treatment services for women diagnosed with breast and cervical cancer. I salute the individuals who spend their time and resources to help these women. But we must not force these women to rely on the goodwill of others.

Right now, the CDC is only screening 12-15% of the women who are eligible. As more women are screened, treatment efforts will become even more difficult. The lack of coverage for treatment services has hurt the program's ability to recruit providers, further restricting the number of women screened.

On top of this, increasing numbers of physicians do not have the freedom under managed care to provide free or reduced-fee services. An article this Spring in the *Journal of the American Medical Association* noted that physicians whose income depends most heavily on managed care, as well as those providers in areas of high managed care penetration, are

providing far less charity care than other physicians.

It is clear that the short-term, ad-hoc strategies of providing treatment have broken down. Because there is no coverage for treatment, state programs are having a hard time recruiting providers; volunteers are spending a disproportionate amount of time finding treatment for women; and fewer women are receiving treatment. We can't expand the program to serve the other 78% of eligible women if we can't promise treatment to those we already screen. That's why I've introduced this important legislation with my colleagues -- it is a long term solution.

This bill gives states the option to provide Medicaid coverage for the duration of breast and cervical cancer treatment to eligible women who were screened and diagnosed with these cancers through the CDC program. This is not a mandate for states. It is the federal government saying to the states "we will help you provide treatment services to these women, if you decide to do so." By choosing this option, states would extend the federal-state partnership that exists for the screening services in the CDC program to treatment services.

I'm proud that my own state of Maryland realized the importance of providing treatment services to women who were screened through the CDC screening program. Maryland appropriated over $6 million in state funds to establish a Breast and Cervical Cancer Diagnostic and Treatment Program for uninsured, low income women. The program has provided services to over 13,300 women in Maryland. The breast cancer mortality rate in Maryland has started to decline, in part because of programs like the CDC's. But not all states have the resources to do what Maryland has done, and even Maryland is not able to fully meet the need for diagnostic and treatment services. That's why this bill is needed. In Maryland alone, passage of this bill would enable my state to provide diagnostic and treatment services to twice as many women as are currently served.

This bill is the best long-term solution. It is strongly supported by the National Breast Cancer Coalition representing over 500 organizations and more than 60,000 individual women, their families and friends; the American Cancer Society; the National Association of Public Hospitals and Health Systems;

the National Partnership for Women and Families; YWCA; National Women's Health Network; the American Medical Women's Association, and many more.

I know that the Senate is supportive of providing treatment services to women diagnosed with breast and cervical cancer through the CDC program. Our bill has 46 cosponsors. And in 1997, the Senate passed a similar provision in the Senate version of the Balanced Budget Act providing Medicaid coverage for breast cancer related services to women diagnosed with breast cancer through the CDC screening program.

Let's act this year to pass the Breast and Cervical Cancer Treatment Act. It is an outrage that women with cancer must go begging for treatment, especially if the federal government has held out the promise of early detection. I hope that this year we can fulfill our promise to the women diagnosed with breast or cervical cancer through the CDC program. Again, I thank you, Senator Chafee, for your strong leadership and commitment to this issue. I will fight to see this legislation passed, and work with my colleagues here today to guarantee that low income women get the cancer treatment they need.

REMARKS

Testimony to the Health Care Subcommittee
Of the Finance Committee
United States Senate

By First Lady of Rhode Island
Marilyn Almond

Supporting Senator Chafee's
Breast and Cervical Cancer Treatment Act of 1999

July 27, 1999

I'd like to thank Senator Chafee and all of the members of the Committee for giving me the opportunity to testify today.

Over recent years, I have taken an active role in paving the way for women to lead healthy fulfilling lives. As you may be aware, Rhode Island has one of the highest mortality rates in our nation from breast cancer. My husband and I have worked with the Rhode Island Breast Cancer Coalition to assist them in their ongoing mission to eradicate this disease.

Through our concerted efforts, our state employees raised over 17 thousand dollars for research through the First Annual Lee National Denim Day last year. Proceeds from this event were distributed to national foundations as well as the Rhode Island Breast and Cervical Cancer Foundation.

To decrease the number of individuals who have been afflicted with this disease, my husband directed our Department of Health to develop a strategic plan to lower the incidence of breast cancer and all other types of cancer among Rhode Islanders.

As part of this strategic plan, the Department publishes a Cancer Control Report Card to enable us to evaluate our success in reducing cancer among Rhode Islanders.

According to statistics compiled last year, more and more women ages 40 through 49 are receiving mammographies, and mortality from breast cancer is down. However, the number of women with cervical cancer is up. While we are working hard to combat this disease, we need to do more. That's why I am here today.

Imagine being diagnosed with breast or cervical cancer. Imagine being informed that you cannot receive the medical treatment you need because you lack medical coverage. Imagine the sense of hopelessness you'd feel. We don't want one woman to experience that. We don't want one woman to face such anguish. Not one.

Since the inception of the Department of Health's Women's Cancer Screening Program four years ago in Rhode Island, nearly 4 thousand economically disadvantaged women have received mammograms and 4 thousand 700 women have had Pap tests in our state.

The Rhode Island Department of Health has effectively teamed up with community organizations to create a network of free medical care for women who have been diagnosed with breast or cervical cancer.

However, with more and more physicians moving into managed care, we have seen a dramatic decline in the number of medical professionals available to provide free medical care. We must create a long-term solution to this problem. That's why the need for this legislation is paramount.

In Rhode Island, we are committed to participating in a program that will provide economically disadvantaged women with comprehensive treatment for their cancer. We need the support of an enhanced match from the federal government to our State's Medicaid program to accomplish this.

You and I both know that screening for breast and cervical cancer alone does not save lives. It's an important first step which must be coupled with the appropriate medical treatment. These women are our mothers, daughters, sisters, granddaughters, aunts and friends. We cannot afford to have promising lives cut short by this disease.

That's why we must ensure that women who are diagnosed with breast or cervical cancer receive the proper medical care.

Whether it's enacting legislation requiring medical insurers to cover hospital stays of up to 48 hours for women undergoing mastectomies or whether it's advocating for this Senate bill today, Rhode Island is a leader in promoting legislation affecting women with breast cancer and all citizens with cancer.

We look forward to the many benefits that this measure will bring to women in our state. We will continue to set a positive example for other states to follow by encouraging them to participate in the program established by this legislation.

Senator Chafee has long been a champion of health care in Rhode Island and in our nation. I know that Senator Chafee's legislation will have a far-reaching impact upon so many women. My thanks to Senator Chafee and to Rhode Island's Congressional delegation for advocating for this bill.

Today, I urge the members of the Committee to support this important legislation.

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US SENATE FINANCE COMMITTEE

HEALTH SUBCOMMITTEE

HEARING ON S. 662

JULY 27, 1999

BARBARA D. MATULA

DIRECTOR, HEALTH CARE PROGRAMS

NORTH CAROLINA MEDICAL SOCIETY FOUNDATION

Thank you, Senator Chafee, for caring about victims of breast and cervical cancer and all the vulnerable adults in this country who desperately need our help.

I have worked with Medicaid for over 20 years, seventeen of them as Director of the program in North Carolina, and although some would say that it is easier to explain the meaning of life, I would like to take a moment to explain Medicaid eligibility rules.

It is widely believed that Medicaid is a health insurance program for the poor. The general public thinks that if you have limited means (low income, little or no assets) and you become seriously ill, requiring extensive and expensive medical care, you can qualify for Medicaid.

This is true for some people, but not for the vast majority of adults under the age of 65.

If you are poor and pregnant, Medicaid will help.
If you are poor and raising a family, Medicaid will help.
If you are a child in a low-income family, Medicaid will help.
If you are over 65 and cannot afford your Medicare premiums, Medicaid will help.
If you are in a nursing home, and have exhausted your private resources, Medicaid will help.
If you are severely disabled for the long term, either mentally or physically, and unable to work, Medicaid and, eventually, Medicare will help.

But if you are a single or childless adult, or if your children are grown, and you become critically ill, regardless of how poor you are, regardless of how desperately you need care, Medicaid cannot come to your aid until your illness has reached the stage when you will die or become permanently incapacitated.

The federal rules governing Medical Assistance for adults who are not caring for minor children require that you have a condition so severe that it will last for at least 12 consecutive months, take you out of the workforce (permanently, in most cases) or result in death.

This means that if treatment can result in recovery within the year, you are not eligible for help.

This means that if you are able to return to the workforce, you are not eligible for help.

This means that if your disability is "temporary" and treatable in less than a year, you are on your own. It does not matter how poor you are or how expensive the medical care will be, you are on your own.

Imagine now that you go home tonight and learn the horrifying news that your mother, or your sister, or your wife, or your daughter or your best friend has found a suspicious lump, or that the results of her pap smear require further testing. Your first response is to

consult with her doctor to find the best surgeon, the best hospital, the best treatment opportunities available. You hope that the problem was detected early. You know that she has regular checkups and this lessens your fears. You are not thinking about the cost of treatment, only about a full recovery. But you are frightened, nevertheless.

Now imagine that you are a woman with no health insurance, no regular source of medical care and you receive the same news from a public health nurse who encouraged you to have the first cancer screening of your life. You, too, are frightened. You worry about your job. There are no sick leave benefits. You worry about how you will pay your bills if you are not working. You worry about where you will go for further diagnosis and if it is called for, the surgery and therapies that you have only heard about, but which you already dread. You have only several hundred dollars in savings. You apply for financial help from the local cancer program, funded by the State, only to learn that it has run out of money for this fiscal year, or that your income is several hundred dollars above the limit (which had to be lowered because of insufficient funds last year). You are told that a public hospital, in another county, may have an opening in their diagnostic clinic in a month or two. You do not know who your surgeon will be. You do not know how you will arrange transportation for follow-up therapies. You do not know where to turn for help.

This bill that you are considering today would allow women who have been identified through CDC's Breast and Cervical Cancer screening programs to receive Medicaid's help for the diagnosis and active treatment of their disease. It limits eligibility to women whose incomes fall below 200% of poverty, or $16,480 per year ($22,120 per couple). It limits the period of eligibility to the time needed for active treatment. It is, in my opinion, the very least we can do.

Will Medicaid programs be able to handle short-term eligibility based on a medical need? Yes. They do so now with Medicaid for pregnant women, which is triggered by a medical need (pregnancy) and ends 60 days after delivery.

Will Medicaid programs work with CDC to develop guidelines for eligibility and referrals? Yes. State Medicaid programs have developed good working relationships with other public health agencies to improve the delivery of care to their constituents.

Will States object to this new category of eligibility? No. Because it is optional and not mandatory, each State will have the opportunity to decide whether it is more cost effective to spend State-only dollars on diagnoses and treatment, or whether those State funds would be better used as match for the federal Medicaid funds that would be available under this bill.

Denying eligibility for medical assistance when early treatment may mean a full recovery and a return to a productive life is fiscally irresponsible and morally indefensible. I hope that you will vote to approve this bill.

Carolyn Tapp
President
Women of Color Breast Cancer Survivors Support Project
Los Angeles, California
July 27, 1999

My name is Carolyn Tapp, President of the Women of Color Breast Cancer Survivors Support Project, located in Los Angeles, California. The Women of Color Project was established in 1991 to link African American survivors to one another and to resources and services. Our mission is to help our sisters survive through the storm of breast cancer. To date WOC has provided support to over 200 breast cancer survivors as well as over 2,500 African American women at risk through our "Each One Teach One" Breast Health Education Seminars.

I appreciate the opportunity to testify before you today and to speak on behalf of the brave women I work with everyday who fight breast cancer against tremendous odds. Being diagnosed with breast cancer is devastating. For women who are poor, African American, and have no health insurance to pay for their treatment -- it often feels hopeless.

Many women in my program were diagnosed with breast cancer through the federal screening program. This program gives women the promise of early detection of breast cancer -- when there is the best chance of survival -- even when they don't have private health insurance. Once diagnosed, however, these women face serious problems finding treatment services. That is where we come in —to help connect them with those services and to provide support.

For these breast cancer patients there really is no system of care — and the care they do receive is partial and very often inadequate. Treatment services are difficult to find; increasingly physicians have not been willing to provide their services for free or for little charge.

For these breast cancer patients there really is no system of care — and the care they do receive is partial and very often inadequate. Treatment services are difficult to find; increasingly physicians have not been willing to provide their services for free or for little charge. The women we see often have to wait for care; or wait to see if they qualify for Medi-cal (the Medicaid system in California). Most often they end up at public health facilities or end up with medical bills in the thousands of dollars that they will never be able to pay. A dear woman in our program just passed on after waiting for six to seven months to qualify for Medi-cal so she could get treated. The Medi-cal eligibility came one day before she died from breast cancer.

We find that the women we serve often make medical decisions about the type of treatment they get based on whether they will have to pay for the care. For the last few years, California had a fund of private dollars donated by the California Wellness Foundation to treat women with breast cancer. The funding for that program no longer exists -- but when it was available -- it only covered one year of treatment. Because of the limited funding, women chose to have radical mastectomies even when breast conserving treatment was recommended. The women were afraid that when the funding ran out they wouldn't be able to pay for chemotherapy and radiation. They were fearful that there would be no treatment available to them if their cancer recurred.

This just isn't right. Women should be able to make decisions about their treatment based on good medical recommendation -- not based on fear because they can't afford treatment like chemotherapy and radiation. I would also like to tell you about the many women who do get treated -- some at public facilities -- that receive horrible inadequate care. Some women we see are talked into radical mastectomies because the physicians know they don't have insurance and can't pay. These women do not get reconstructive surgery and have to live, not only with

horrible scars, but also with terrible side effects from bad care. There doesn't appear to be any accountability among some of the doctors who end up treating poor African American women. The women we see find themselves at the mercy of a system that doesn't really serve them. It is full of cracks and holes and the women we see every day slip through them. Last year 13 women in our group died; this year so far, 4 more women have died. Many more suffer from inadequate care. We do our best to help them and to reach out to the community to find better services. But we see far too much suffering.

But having a law that ensured that each woman received good care, for all the services that are medically necessary for treating breast cancer is what is necessary to close the gap between screening services and medical treatment. The women at our project deserve the same chance of survival, with the same quality of life as all women who find they have breast cancer. That is the promise of the screening program that sought to reach out to underserved communities like mine. Its time Congress made good on that promise by passing this treatment bill.

Thank you.

Testimony of Barbara Flett, RN
Director of the Women's Health Partnership of Suffolk County
before the Senate Finance Committee
Subcommittee on Health Care
July 27, 1999

Thank you Mr. Chairman, and members of the Committee for inviting me to testify today. I am Barbara Flett, RN, Director of the Women's Health Partnership of Suffolk County. The Women's Health Partnership of Suffolk County that I represent is part of the New York State Breast and Cervical Cancer Screening Program. Similar programs exist in every county in the state and in every state in the country.

Congress adopted a National screening program for breast and cervical cancer called the Breast and Cervical Cancer Mortality Prevention Act in 1990 (Public Law 101-354) to allow funding for screening uninsured and underinsured women for breast and cervical cancer. The law prohibits federal resources appropriated for the program to be used for treatment. States are required however, under the law, to assure that women who are screened and diagnosed with cancer through the program receive the treatment they need; yet, the reality is that not all women are treated. Of the women who are treated: some have to wait weeks or months for their care, others receive care that is incomplete or inadequate.

I appreciate the opportunity to testify before you today on behalf of the patients who are screened and diagnosed with breast and cervical cancer through our program. The process of identifying available resources for treatment services is incredibly labor-intensive, and I'm afraid it is causing enormous strain on our program. The time and energy required for follow up is tremendous.

The current ad hoc system of treatment is tenuous and fragile. Resources for treatment are short-term. We do our best to find treatment services through reduced rates or charity care but the lack of coverage for treatment services and the time we must devote to finding treatment diverts resources away from the program. Currently, the Breast and Cervical Cancer Screening Program is only able to screen 12-15% of the eligible women nationwide. I believe that if there was a treatment component, we'd be able to screen more eligible women.

Last year, our program screened 2200 women - 10% of whom required follow up care. Judy Lewis was one of those women, and I'd like to share her story with you today. Judy was diagnosed with Stage 2 breast cancer last year. Prior to her diagnosis, she was a waitress at a local diner where she worked to supplement her husband's income to pay the family's bills and to support her daughter and three grandchildren. Judy's job did not provide health insurance, so when she felt a lump in her breast, she was relieved to find out that she could be screened through the Breast and Cervical Cancer Screening Program.

Her relief did not last long.

Judy Lewis' mammography results came back showing breast cancer. Immediately, we tried to find Judy a doctor who would be willing to provide her with treatment. This was no easy task. After calling many doctors for almost one week, I finally found one who agreed to see Judy. A lumpectomy confirmed our breast cancer diagnosis. As you can imagine, Judy was devastated. In the next five weeks, she required a wider margin biopsy and a partial mastectomy.

Following three surgeries, she needed seven weeks of radiation. In order to get Judy treatment, we were able to convince one doctor to provide his services at one-third the regular cost. Unfortunately, we were unable to obtain similar arrangements with other physicians or the hospital. As a result, Judy now owes bills for her radiation, anesthesiology and other hospital charges and she is in debt more than $20,000.

I tell you Judy's story not so that you will feel sorry for her, but so that you will understand a typical situation faced by women who are screened and diagnosed through our Program. Lack of guaranteed treatment means that there is no way to tell how long a woman will have to wait to get care following a diagnosis of breast or cervical cancer. Moreover, once a woman receives treatment, she often must spend her time arguing with doctors and hospitals (and sometimes creditors) over her bills, rather than focusing on recovering from her devastating illness. No matter how hard Program Directors like my colleagues and I work to find that treatment - and believe me, we work as hard as we can every day to do that - there is no guarantee that we will be able to find treatment for these women.

For some women, the possibility of facing this situation is just too daunting. These are the women who would rather not get screened and not know if they have breast or cervical cancer than be faced with a situation where they can't find - and can't afford the treatment they need.

Dr. Stanley Klausner, a board certified General Surgeon specializing in treatment of diseases of the breast and Director of Breast Services at Brookhaven Memorial Hospital in Patchogue, New York, understands the situations these women face.

Dr. Klausner is one of the physicians who have donated time and treatment to women screened through our Program. In his recent testimony before the House Subcommittee on Health and Environment, Dr. Klausner demonstrated the need to enact the Breast and Cervical Cancer Treatment Act into law. *(Mr. Chairman, may I introduce Dr. Klausner's testimony for the record?)*

Dr. Klausner is all too aware of the difficulty of getting treatment for women who are screened and diagnosed with breast cancer through our program. He believes that with the advent and penetration of managed care fewer and fewer physicians will be able to donate their services.

Dr. Klausner and I have become aware of another, even more disturbing trend. Women in situations like Judy's who, with no insurance, are often afraid to elect breast conserving surgery. They are so terrified of medical bills that their medical judgement is biased. Despite their awareness that their breast cancer may be amenable to breast conserving surgery, these women are electing to have mastectomies instead because they know the cost of the additional treatments following breast conservation are too expensive. A woman should not have to make the difficult decision to sacrifice her breast rather than incur medical bills she cannot pay. As for reconstructive surgery following a mastectomy, this has simply never been an option.

But the problem does not end there.

In Judy's case, and in cases of many women like her, she was unable to afford the physical therapy required following her surgery to regain proper use of her arms. Without this therapy, she was unable to return to work. Left with no job and thousands in bills, Judy is haunted by how she will ever repay her debt. Moreover, she is terrified that her

daughters and granddaughters may someday receive a diagnosis of breast cancer like she did.

One thing Judy Lewis knows for sure. If her daughters or granddaughters, or any other women like her are uninsured and screened and diagnosed through the CDC Program - they should be guaranteed treatment.

Take it from me. Judy was one of the lucky ones. We were able to get her treated in time to save her life - but at a great expense to her and her family. No woman should have to go through what she did - and what women like her go through every day. When a woman is diagnosed with breast or cervical cancer, she should not have to worry about when or whether she will be able to find treatment. If Congress cared enough about reducing the incidence of death from breast and cervical cancer to establish a federal screening program, then Congress should care enough to ensure that there is a treatment component as well. Screening must be coupled with treatment to prevent death from breast and cervical cancer.

Congress must enact S. 662, the Breast and Cervical Cancer Treatment Act - as soon as possible. Women, like Judy Lewis, deserve it. Thank you.

NBCC

NATIONAL BREAST CANCER COALITION

grassroots advocacy in action

Testimony of Marlene McCarthy
Member of the Board of Directors
National Breast Cancer Coalition
before the
Senate Finance Committee
Subcommittee on Health Care
July 27, 1999

Thank you Mr. Chairman, and members of the Committee for inviting me to testify today. I am Marlene McCarthy, Member of the Board of Directors of the National Breast Cancer Coalition (NBCC), serving on the Executive Committee. I have breast cancer, and am one of the 2.6 million women living with this disease in the United States today.

The National Breast Cancer Coalition is a grassroots advocacy organization dedicated to eradicating breast cancer. NBCC seeks to increase the influence of breast cancer survivors and other activists over public policy in cancer research, clinical trials, and access to quality health care for all women. I am sharing with you today a critical concern of NBCC's 500 member organizations and 60,000 individual members.

BACKGROUND

The National Breast Cancer Coalition has made passage of S. 662, the Breast and Cervical Cancer Treatment Act, a top priority. As you know, this legislation would establish a federal treatment component for the Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) that Congress enacted as part of the Breast and Cervical Cancer Mortality Prevention Act in 1990. That program – which has screened more than one-

half million women for breast cancer – does not provide any federal resources to pay for the treatment when women are diagnosed with breast or cervical cancer. Instead, Congress asks participating states to assure that the women who are screened get the treatment they need.

The fact that the CDC Early Detection Program does not cover any costs of treatment for breast and cervical cancer has created a very serious public policy gap. State and local providers and women themselves have been left to scramble for resources to pay for treatment. Women are relying on charity and donated care when it is available and sometimes going into debt when no public or private dollars can be found. The NBCCEDP is a program dedicated to serving low-income women, but at times fails to come through.

Let me be perfectly clear. The individuals who run this program and the thousands of volunteers who help find women treatment do all that they can everyday to ensure that patients diagnosed through the program get the treatment they need. It is the people who do the screening and spend countless hours trying to find treatment who have identified the problems with a system that lacks a treatment component. It is the system that is broken, and we need to fix this problem so that they can screen more women, and not have to spend the majority of their time finding treatment services.

What S. 662 Would Do

NBCC-Personal Stories

Not long after the CDC screening program was enacted into law, Jan Eick-Swigart, an NBCC advocate from California, launched an effort to guarantee treatment for women screened and diagnosed with breast cancer through the federal program.

Prior to losing her battle with breast cancer, Jan wrote a compelling memorandum on the need for a federal treatment component to CDC's Early Detection Program. Her memorandum states:

"One of the heartbreaking ironies about the BCCEDP and other programs that offer underserved women free or low cost mammography is the lack of resources to treat the women who are diagnosed with breast cancer as a result of these programs."

In the years following Jan Eick-Swigart's efforts to ensure that women screened and diagnosed with breast cancer through CDC's federal program are guaranteed treatment through Medicaid coverage, many NBCC advocates have reaffirmed the need for a federal treatment component to this program. Our members have witnessed the delay that can result from having to scramble to find treatment – and the physical and emotional result that delay has on women screened and diagnosed through the program.

A woman in Florida had to wait 5 months before a volunteer found her treatment dollars. This woman had five agonizing months of knowing she was sick and having no way to get the treatment she so desperately needed.

Moreover, we have heard from women who ultimately got treatment, but were then saddled with medical bills that they couldn't pay. Instead of focusing on getting well, these uninsured women have had to focus on how they are going pay for their care.

A woman in Massachusetts, for instance, has already spent her children's college fund for her treatment and is paying off more than $20,000 in medical bills. Her story is incorporated in a statement from Mary Ann Waygan, coordinator for the CDC Breast and

Cervical Cancer Initiative for Cape Cod, Massachusetts. *(Mr. Speaker, may I introduce this statement into the record?)*

A woman in New York said that during her treatment, it seemed that her conversations with her doctors were more about the bills than how to save her life.

There are other women who after having a mammogram find out they need follow-up diagnostic services but refuse to get them. They do not want to know they have cancer without knowing exactly where the treatment dollars will come from.

A woman from Virginia explained she "feels that if she is not diagnosed it is better because she will not have to worry about treatment."

A woman from Maine had an initial mammogram through the NBCCEDP program and the results were "highly suggestive of malignancy." Due to the cost, rather than pursue a biopsy and the treatment, which may have been needed, the client decided to wait and have a repeat mammogram in six months.

Surely, these scenarios are not what Congress intended when it enacted the National Breast and Cervical Cancer Early Detection Program into law. Yet, these scenarios are the reality of what happens when women are screened and diagnosed with breast and cervical cancer through a federal program that does not guarantee federal treatment coverage.

CDC-Case Study

NBCC is not alone in our belief that the CDC Early Detection Program needs a system that provides sufficient funding for treating women. In response to concerns about treatment raised across the country (and raised by advocates like us), CDC

conducted a case study which illustrated a similar conclusion. The study focused on participating states (California, Michigan, Minnesota, New Mexico, New York, North Carolina and Texas) and looked at the treatment following a diagnosis of breast or cervical cancer through the program.

The results of that study, released in January 1998, found that although treatment had been initiated for most of the women in whom cancer was diagnosed, the system of treatment is "tenuous and fragile at best."

(Mr. Chairman, may I introduce the report which summarizes the results of the study into the record?)

The Numbers Don't Tell Us the Whole Story

I want to make very clear that the issue is not just that some women don't get treated. We have had to look beyond the numbers to find the real story. It is behind these numbers that the story exists – the story that women from all over the country come and talk to me about. It's the story that CDC's own study underscores. The story of women – diagnosed with breast and cervical cancer – wondering how and whether and when they'll find treatment for their disease, and then often left with a lifetime of bills to pay for that treatment.

Lack of Treatment Funding Is Diverting Resources Away From the Screening Program

There are several findings that are very telling in the conclusions of CDC's study. First, the study highlights the considerable time and effort involved in developing and maintaining systems for diagnostic follow-up and treatment. It illustrates the labor-intensive process required to identify resources within states to provide diagnostic and treatment services.

NBCC has heard about the serious problems people who run the screening programs across the country have in finding treatment for women diagnosed through the program. The hours spent searching for treatment are diverting resources away from the screening program. As a result, fewer women are being screened. This is very serious - the program currently serves only 12% to 15% of age eligible, uninsured women nationally.

The threat that the lack of treatment funding poses – not only to the woman who have been diagnosed through the program – but also to the women who may rely on the screening services in the future – is lethal. **This** is the story behind the numbers.

It is our hope that in enacting a Medicaid option for these women, they will be presumed eligible for Medicaid on the first day that they are diagnosed. This way – they know they'll get the immediate care they need instead of facing delays and wondering how and whether they'll get treated. This way – program coordinators can focus their efforts on increasing the number of women they are able to screen for breast and cervical cancer.

In the Context of an Evolving Health Care System

Second, the CDC study puts this issue in the context of an evolving health care system. The study highlights what we too are hearing from our advocates around the country– an increasing number of physicians who do not have the autonomy, because of the changes in the health care system, to offer free or reduced-fee services to NBCCEDP clients.

Mr. Chairman, I point you to a letter from Robert Brooks, MD, Secretary of the Department of Health for the Florida Department of Health and Human Services.

(Mr. Chairman, may I submit this letter for the record?)

In his letter, Dr. Brooks writes, "We are starting to see the strain our providers are experiencing through their support of the program...One county program had had three women diagnosed with breast cancer during their first two years in operation; each one cared for by a different provider. Since October, 1998, five additional women have been diagnosed and approximately ten to fifteen more have abnormal clinical breast exam or mammogram results and could be diagnosed with cancer. Needless to say, the providers are concerned with these increasing numbers. Some of the providers have asked the local program coordinator not to refer additional patients to them for the remainder of this program year..."

"...Another county program has seen a total of ten women with cancer and they have two to three physician providers and one hospital provider who agrees to see program clients. Three providers have also expressed alarm at the number of women with abnormal exams who are referred to them for care. We have been told that these

current providers may not be willing to support the Program when this county renews their program agreement this October..."

And the stories go on.

Dr. Brooks concludes with the fear that Florida's providers continue to show signs of abandoning this program unless they are provided with some assistance that is not available through the CDC grant.

Florida, a state with the highest degree of managed care penetration in the country, is perhaps one of the best (but certainly not the only) example of a situation where the lack of availability of treatment can only get worse, and where any attempts to expand the screening program are hindered.

It is important to note that as managed care continues to expand across the country, more and more doctors may have less autonomy to provide the charity care relied on by NBCCEDP coordinators. To illustrate this point, a recent survey based on 12,000 U.S. physicians was published in the April 1999 issue of the *Journal of the American Medical Association.* The study finds that doctors whose income depends most heavily on health maintenance organizations and other managed-care health plans, on average, devote only half as much time to charity care as do their colleagues who don't participate in managed care.

What will this mean for the people who run the NBCCEDP programs who are already spending countless hours searching for treatment for women diagnosed with breast and cervical cancer? What will this mean for women who are already suffering a delay in treatment? Or who are saddled with treatment bills they can't pay? Or who are reluctant to get screened because they "prefer not to know" if there is no treatment

available? What will this mean for the ability of the National Breast and Cervical Cancer Early Detection Program to sustain itself?

Precedent in the Medicaid Program

Respondents in CDC's study suggest a similar solution to the lack of funding for treatment that we bring before you today – a solution that passage of S. 662 would guarantee. That solution is a provision of treatment services assured through a federal "Medicaid option" which would give state Medicaid programs permission to allow eligibility to BCCEDP clients who are diagnosed with cancer through the program. This would include those women who are eligible for BCCEDP services but whose incomes and/or assets exceed Medicaid limits.

There is a precedent for covering participants in the Breast and Cervical Cancer Early Detection Program under Medicaid. In 1993, Congress created the Tuberculosis Optional Benefit Program, making individuals who are infected with tuberculosis eligible for Medicaid.

Mr. Chairman, and Members of the Committee, as the stories of NBCC's advocates and as the results of CDC's own study show – what we have today is an ad-hoc system that is incapable of serving the future needs of the program and the women it serves. Solutions in the vast majority of states are short-term, tenuous and fragile. The fact that so many women eventually get treated reflects the dedication of providers and volunteers who spend enormous effort and time to find treatment services. Yet, while the majority of women get care, there is no system of care. As a result, some women

experience unnecessary delays or are lost to follow-up care, and a few don't get treated at all.

Our message is not to put an end to the screening program. It is to finish the work Congress initiated in 1990 by adopting a treatment component that will serve all the women screened and diagnosed with breast and cervical cancer through this program.

How This New Treatment Program Would Work

Enactment of S. 662 would allow the women who are eligible for the CDC Early Detection program -- that is women who are between 200 percent and 250 percent of poverty depending on their state and who are not already insured -- to receive their treatment through the state Medicaid program. States would not be required to participate, but those that do will receive an enhanced match – 75 percent federal dollars and 25 percent state dollars.

NBCC is heartened by the support for this legislation from you, Mr. Chairman, and from the Committee. We know that this Committee passed similar legislation as part of the budget reconciliation bill in 1997. We are pleased that this year, many Members of this Committee have come together in a bipartisan way to cosponsor S. 662, in recognition that screening must be coupled with treatment if we are to achieve a reduction in mortality.

We now ask the Committee to ensure that happens as the screening program grows by enacting S. 662, the Breast and Cervical Cancer Treatment Act this Congress.

Mr. Chairman, and members of the Committee, thank you again for the opportunity to testify. We look forward to working with you on this critically important issue. I'd be happy to answer any questions you may have.

Follow-Up and Treatment Issues in the National Breast and Cervical Cancer Early Detection Program

Study Results
January, 1998

Acknowledgments

- Funding for this study was from the Centers for Disease Control and Prevention, Division of Cancer Prevention and Control
- The study was designed and implemented by a team of investigators from Battelle Centers for Public Health Research and Evaluation and the University of Michigan School of Public Health

Research Team

Battelle Centers for Public Health Research and Evaluation:

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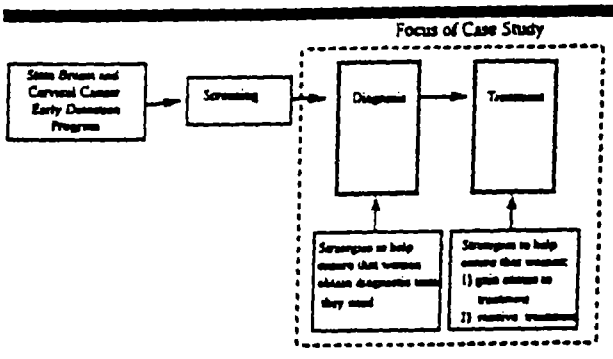
Goals of the Study

- To document strategies and methods used by states to obtain follow-up diagnostic services not covered by NBCCEDP funds.
- To document strategies and methods used by states to obtain treatment services for clients diagnosed with CIN or cancer.
- To identify strategies that are perceived as successful or innovative in securing diagnostic and treatment resources.

Flow of Follow-Up and Treatment Activities



Research Questions

- What guidelines, policies or methods have been developed and implemented by states to ensure that women with abnormal screening results and women diagnosed with cancer or precancerous lesions receive diagnostic follow-up and treatment services?
- How is the component of the program that identifies and secures diagnostic and treatment services organized?
- What role do coalitions or other partnerships play?

Research Questions

- Have the methods or tactics being used to identify and secure diagnostic and treatment resources changed with time, and do they differ within the individual state programs or across programs?
- What are the key lessons learned regarding diagnostic and treatment services in a program such as the NBCCEDP?

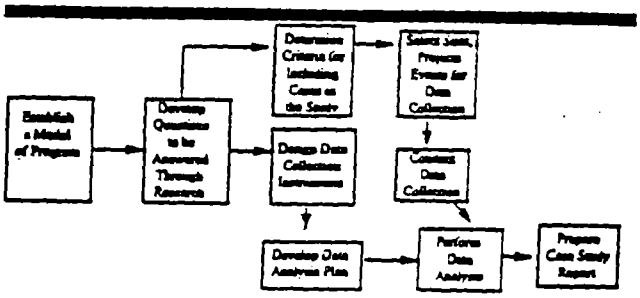
Phases of the Study

- **Phase I:** Core set of data on 35 programs
- **Phase II:** In-depth case study of 7 states
- **Phase III:** Linkage study (in process)—Tumor registry data and program data from 3 states (CA, MI, NM) were linked to document timing of treatment initiation and initial course of cancer treatment

What is a Case Study?

- A case study seeks to understand the way in which a program, system, or organization works within its everyday setting
  - » It focuses on a particular problem, issue, or structure which is studied in relationship to the larger program, system, or organization
- While describing this relationship, the case study may or may not lead to conclusions about outcomes
- A case study uses all appropriate sources of evidence – written, observational, and interview – that may be analyzed both qualitatively and quantitatively

Conducting a Case Study



Case Study Selection Criteria

- Provided screening for at least three years
- Diagnosed 60 or more breast cancers since screening began
- Representative of the following stratification criteria:
  - » Centralized versus decentralized programs
  - » Geographic region of United States
  - » Urban/rural mix of the population
  - » Racial and ethnic diversity among program clients

Case Study States

State	Number of Breast Cancers Diagnosed	Region
California	168	West
Michigan	249	Midwest
Minnesota	137	Midwest
New Mexico	169	West
New York	173	Northeast
North Carolina	106	South
Texas	107	South

How Did We Conduct the Case Study?

- Contacted the coordinator for each of the seven programs to schedule site visits, and to obtain background information
- Reviewed documents supplied to us by the state program, such as organizational tables, reports and articles
- Traveled to each state and briefed state BCCEDP staff regarding the project at the beginning of each state's site visit

How Did We Conduct the Case Study?

- Interviewed State BCCEDP Coordinator and other staff who work with diagnosis and treatment issues
- Interviewed local coordinators and providers in a variety of settings throughout the state
- Interviews were tape recorded, transcribed, and entered into a word processing database

How Did We Analyze the Data and Write the Case Study State Summaries?

- The Project PI and the Case Study Coordinator developed a codebook based on the research questions in the Case Study Protocol
- Using the codebook, the PI and Coordinator worked together to achieve 80% inter-rater agreement on the use of codes for text, and then trained one other team member
- All interviews were coded and entered into a text analysis software

How Did We Analyze the Data and Write the Case Study State Summaries?

- Using the analyzed transcripts, a member of the site visit team developed a state summary
- Each member of the site visit team reviewed the state summary
- The summary was then sent to state program staff and other interviewees for review
- Reviewer feedback was incorporated into a revised state summary

Case Study Results

- Site visits were conducted February-June, 1997
- A total of 126 interviews were conducted
- A total of 192 people were interviewed

Number of Interviews by State and Role

	TOTAL	CA	MI	MN	NM	NY	NC	TX
State staff	58	13	4	11	4	9	10	7
Local staff	15	2	2	2	4	4	-	1
Screening provider	60	3	6	8	5	7	23	8
Dx or Tx provider	45	7	4	9	3	3	13	6
Advisory Board\ Coalition member	10	2	-	1	3	1	2	1
Other	4	-	-	1	2	-	1	-
TOTAL	192	27	16	32	21	24	49	23

Strategies Used to Ensure Provision of Diagnostic and Treatment Services

Common Approaches at the State Level:

- Clients followed through use of tracking and follow-up systems
- Requirements in contracts with providers
- Appeals to providers through state medical societies, professional associations, etc.

Strategies Used to Ensure Provision of Diagnostic and Treatment Services

Common Approaches at the Local Level:

- Bill insurance
- Assist clients in applying for Medicaid, Hill Burton funds, other assistance programs
- Referral to public hospital
- Charity care, donated services
- Case rotation
- Reduced fees
- Negotiated payment plans
- Clients pay fee for service

Additional Strategies Used by States

• Blue Cross Foundation treatment fund	CA*
• Race for the Cure fund	MN*
• State breast cancer programs	NY*
• Other state funds	TX*, NC
• Tobacco excise tax fund	CA*, MI
• Providers of last resort	NM, TX
• County indigent funds	NM, TX

* funds used for breast services only

General Findings Across States

- States have found supplemental funds (primarily for breast cancer diagnostic services)
- Women diagnosed with cancer who want to be treated are receiving treatment
- Strong reliance on providers to find resources
- Follow-up handled on case-by-case basis

General Findings Across States

- Solutions, strategies and networks are tenuous and fragile
- Programs operate within changing health care environments (i.e. growth of managed care)
- Information lacking for many important issues:
  - payment source for diagnostic and treatment services
  - out-of-pocket expenses for women
  - impact of financial barriers on time delays/refusals

Strengths

- Women who need and want cancer treatment are receiving it
- Creative responses and strong partnerships have emerged at state, local and provider level
- Availability of state or foundation funds to supplement Federal resources

Strengths

- Centralized tracking systems work well
- Program has had positive effect on tracking and follow-up in larger community

Areas of Concern

- Lack of financial support for diagnosis and treatment
- Time and energy required for follow-up is tremendous
- Burden of follow-up has led to restrictions in number of women screened
- Several barriers to provider recruitment:
  - low reimbursement rates (mandated by Congress)
  - lack of coverage for all diagnostic follow-up services
  - liability for treatment
  - administrative burden of follow-up

Areas of Concerns

- Some women experience time delays or are lost to follow-up (especially in regard to cervical services)
- A small number of women have refused cancer treatment
- Coordinating diagnostic follow-up is greater burden than arranging treatment
- Resources states have developed are short-term solutions, and difficult to manage/administer

Areas of Concern

- Categorical nature of program prohibits a more comprehensive approach to women's health
- Financial access is only one dimension of access to health care services. Many non-financial barriers impede follow-up care:
  - logistical barriers (e.g. transportation, scheduling)
  - cultural barriers (e.g. language barriers, fatalistic attitudes, fear)
  - immigration issues

Respondent Recommendations

- Program should pay for all diagnostic and treatment services, or at least through definitive diagnosis
- Allow state resources used for all diagnosis and treatment services to be counted in the 3:1 match
- Cover anesthesia and other affiliated services
- Increase reimbursement rate for services covered
- Increase support for case management and community infrastructure
- Universal health insurance

Conclusions of Case Study

- Strong response to provision of diagnostic follow-up and treatment services has emerged
- Wide range of strategies is employed within states; effort at local level is tremendous
- Responses that have emerged are administratively cumbersome and unstable; long-term solutions are needed
- Strong commitment to continued growth and success of the NBCCEDP exists at state and local level

Linkage Study – Research Questions

- What proportion of women identified through selected states' BCCEDPs as having breast or cervical cancer did not receive an initial course of treatment, based on registry records?
  - » What characteristics of women and their cancers are associated with not receiving treatment?

Linkage Study – Research Questions

- What are the components (surgery, radiation, chemotherapy, hormonal therapy) of the initial course of cancer treatment for women identified through the BCCEDPs as having breast or cervical cancer?
  - » What characteristics of women and of their cancers are associated with the content of the initial course of treatment?

Linkage Study – Research Questions

- What is the time interval between abnormal screening and diagnosis?
- What is the time interval between diagnosis and treatment?
  - » What characteristics of women and their cancers appear to be related to these time intervals?

Linkage Study – Research Questions

- How does the information from the program database compare with the corresponding information from the cancer registry database?
- How do women screened through the program compare with all women in the registry with regard to patterns of diagnosis and treatment?

CDC

March 27, 1998 / Vol. 47 / No. 11

MMWR

MORBIDITY AND MORTALITY WEEKLY REPORT

Imported Dracunculiasis — United States, 1995 and 1997

Dracunculiasis is a parasitic infection caused by a filarial worm (*Dracunculus medinensis* [i.e., Guinea worm]) that is transmitted through contaminated drinking water. Approximately 1 year after a person is infected, one or more meter-long adult female worms begin to emerge through the skin, often incapacitating the patient for ≥2 months. Despite a dramatic decrease in cases worldwide, dracunculiasis is still occasionally imported into the United States. Since 1995, two cases of dracunculiasis have been reported in the United States, both imported from Sudan. This report summarizes the investigation of these cases.

Patient 1. A 9-year-old girl residing in Tennessee had emigrated from Sudan in September 1995 (*1*). Before the girl left Sudan, a Guinea worm had emerged and had been extracted from her right lower leg. The lesion had healed when she arrived in the United States. After she had been in the United States for 3 weeks, another Guinea worm began to emerge from her left leg. Medical examination at a local health clinic revealed a string-like worm dangling from a lesion on her left leg, and she was referred to an infectious disease specialist. The leg was secondarily infected and swollen, and the girl was unable to walk. Despite antibiotic treatment, her cellulitis did not improve, and the lesion was surgically opened, drained, and debrided of pus, necrotic debris, and fragments of the Guinea worm. The patient was hospitalized for 2 weeks, requiring surgery to stretch a contracture of her ankle and to apply a skin graft to the wound. After outpatient physical therapy, she was able to walk without crutches.

Patient 2. A 31-year-old woman residing in Connecticut had emigrated from Sudan in January 1997. In April 1997, she was evaluated at a university clinic for possible tuberculosis (TB). A radiograph revealed lung lesions consistent with TB and a worm-like calcification in her left chest. Physical examination revealed multiple, indurated, oval lesions 4–8 cm in diameter on both lower legs. The patient reported the lesions had been present for 1 year and were intermittently painful. She recalled that a long string-like worm had emerged from her leg during the previous year. Biopsy of the leg lesions revealed erythema induratum, consistent with Bazin disease, a cutaneous manifestation of TB. The patient had evidence of a dead and calcified Guinea worm in her chest and a history suggesting a live Guinea worm had emerged from her leg before she arrived in the United States. She also had pulmonary TB with a cutaneous tuberculid skin manifestation. Treatment with isoniazid, rifampin, and pyrazinomide

HIV Counseling and Testing — Continued

ing that persons who receive preliminary results understand the meaning of the result and prefer rapid testing (*4*). When additional rapid tests become available for use in the United States, the PHS will re-evaluate algorithms using specific combinations of two or more rapid tests for screening and confirming HIV infection.

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Strategies for Providing Follow-Up and Treatment Services in the National Breast and Cervical Cancer Early Detection Program — United States, 1997

The Breast and Cervical Cancer Mortality Prevention Act of 1990* authorized CDC to establish the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to increase screening services for women at low income levels who are uninsured or underinsured (*1*). Although the NBCCEDP covers most diagnostic services that women need after receiving an abnormal mammography or Papanicolaou (Pap) test result, the program does not reimburse for breast biopsies. In addition, the Act prohibits the use of NBCCEDP funds for cancer treatment. Participating health agencies must ensure that NBCCEDP clients receive timely, appropriate diagnostic and treatment services. In 1996, CDC began a case study to determine how early detection programs in seven participating states (California, Michigan, Minnesota, New Mexico, New York, North Carolina, and Texas) identified resources and obtained diagnostic and treatment services. This report summarizes the results of the study (*2*), which indicate that respondents in these states reported that treatment had been initiated for almost all NBCCEDP clients in whom cancer was diagnosed. However, respondents also considered the strategies used to obtain these services as short-term solutions that were labor-intensive and diverted resources away from screening activities.

In the seven states, NBCCEDP-sponsored screening services had been provided for ≥3 years, and breast cancer had been diagnosed in ≥60 women. The states were se-

*Public Law 101-354.

National Breast and Cervical Cancer Early Detection Program — Continued

lected to provide a range of geographic locations, a combination of urban and rural populations, and racial/ethnic diversity among program clients. Researchers conducted semi-structured interviews with 192 persons affiliated with the seven state programs. Of these interviewees, 120 (63%) were providers of screening, diagnostic, and/or treatment services; 58 (30%) were state program staff; and 14 (7%) were coalition members. Interviews included topics such as guidelines related to diagnostic and treatment services, strategies used to obtain and pay for services, level of effort required to secure these services, and changes in strategies over time. Each interview was tape recorded and transcribed. Using a systematic scheme derived from the research questions, three researchers coded the same transcripts until an inter-rater agreement of 80% was reached. Thereafter, all transcripts were coded independently. Coding results were entered into text analysis software that sorts text from transcripts into sets of information, themes, and evidence relevant to the specific research questions (*3*). The results reflect a synthesis of the interviewees' responses.

Respondents described several strategies used to ensure necessary diagnostic and treatment services for women screened through the NBCCEDP. State-level strategies in all states included 1) computerized tracking and follow-up systems that used program surveillance data to identify and manage clients in need of diagnostic and treatment services; 2) provisions in contracts requiring screening providers to arrange for diagnostic follow-up and treatment before screening women; and 3) arrangements with provider groups and state professional associations for free or reduced-cost services for NBCCEDP clients. All states also had access to public or private funds to help support services not covered by the program; such revenue sources included state appropriations from general or tobacco tax revenues or funds from private foundations. These funds were available primarily for breast diagnostic services.

Local strategies tailored to the needs of individual clients were used to obtain diagnostic and treatment services. Common strategies reported by respondents included the following: providers billed public or private insurance plans; providers or local health departments helped clients apply for public assistance programs; providers referred clients to public hospitals; county indigent-care funds and hospital community-benefit programs financed services; clients received services through individually negotiated payment plans; and clients paid reduced or full fees for services.

Respondents strongly supported the continued growth of NBCCEDP and its goals but expressed several concerns. First, considerable time and effort were involved in developing and maintaining systems for diagnostic follow-up and treatment. Second, the process of identifying available resources within states for diagnostic and treatment services was considered labor-intensive. Third, the lack of coverage for diagnostic and treatment services negatively affected recruitment of providers and restricted the number of women screened. Fourth, respondents believed that an increasing number of physicians will not have the autonomy, because of changes in the health-care system, to offer free or reduced-fee services to NBCCEDP clients.

Respondents reported that arrangements for treatment were made for almost all NBCCEDP clients who received a diagnosis of breast cancer or invasive cervical cancer. Respondents stated that some women experienced time delays between screening, definitive diagnosis, and initiation of treatment. State program officials reported that, according to 1992–1996 surveillance data, small numbers of clients in whom cancer was diagnosed (i.e., from three to 13 women in each state) subsequently refused

National Breast and Cervical Cancer Early Detection Program — Continued

treatment. Because these clients were not interviewed, it could not be determined whether financial barriers contributed to their decisions to refuse treatment or their loss to follow-up.

Respondents were concerned that the NBCCEDP did not provide funding for all diagnostic procedures and treatment for the diseases for which clients were being screened; approaches for delivering services were fragmented; and the process of obtaining resources required substantial effort at the state, local, and provider levels. Respondents reported that the continuation of every strategy for diagnostic and treatment services beyond the next few years is uncertain.

Reported by: PM Lantz, PhD, Univ of Michigan School of Public Health, Ann Arbor. LE Sever, PhD, Battelle, Centers for Public Health Research and Evaluation, Seattle, Washington. Program Svcs Br, Office of the Director, Div of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, CDC.

Editorial Note: During July 1991–March 1997, the NBCCEDP provided 576,408 mammograms to women aged ≥40 years, and 3409 cases of breast cancer were diagnosed. During this same period, the program provided 732,754 Pap tests; 23,782 cases of cervical intraepithelial neoplasia and 303 cases of invasive cervical cancer were diagnosed. These totals included women referred to the program for diagnostic evaluation of an abnormal screening result. The NBCCEDP internal estimates suggested that during this period only 12%–15% of uninsured women aged 40–64 years in the United States had been screened by the program (CDC, unpublished data, 1997).

Screening alone does not prevent cancer deaths; it must be coupled with timely and appropriate diagnostic and treatment services. The Congressional mandate for NBCCEDP requires grantees to take all appropriate measures to ensure provision of services required by women who have abnormal screening results. CDC provides funds for case management to help these women access health-care services. To increase the comprehensive nature of the program, CDC recently approved the use of NBCCEDP funds for breast biopsies.

The results of this study indicate that state health departments and their partners in the seven states had developed a wide range of strategies for diagnostic and treatment services in the absence of program resources. However, the time and effort required to arrange and maintain these services diverted resources away from screening activities.

This study was subject to at least two limitations. First, the results were based solely on the experience and opinions of informed professionals affiliated with the program and did not include the perspectives of NBCCEDP clients. Second, the results may not reflect the program experiences in other states. Case-study methods, however, are an appropriate and well-accepted approach to gaining in-depth understanding of complex programs in real-life situations (4). The validity of the findings was enhanced by developing standard instruments to guide the semi-structured interviews, protecting the confidentiality of respondents' remarks, using interview transcripts for data analysis rather than relying on interviewer notes, and obtaining feedback concerning state summary reports from respondents.

As more women are screened by the NBCCEDP, a greater burden will be placed on participating health agencies, providers, and other partners to obtain resources for breast and cervical cancer treatment. Case-management services will continue to be essential in helping underserved women overcome financial, logistical, and other bar-

National Breast and Cervical Cancer Early Detection Program — Continued

riers to receiving these services. Other long-term solutions to ensure that women in the program receive necessary treatment services are being pursued.

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Notice to Readers

World Health Day — April 7, 1998

"Invest in the Future: Support Safe Motherhood" is the theme in the United States for World Health Day, April 7, 1998. In the United States, this day will focus on the continued importance of maternal health and opportunities to improve this aspect of women's health. Although the risk for women dying from pregnancy has decreased substantially during the past 50 years, the maternal mortality ratio for the nation has not decreased since 1982 (*1*). Approximately 50% of pregnancy-related deaths remain preventable (*2*), and the extent of morbidity associated with pregnancy is often unrecognized.

Safe motherhood begins before pregnancy with healthy lifestyles that include good nutrition, physical activity, preconception care, and avoidance of harmful substances. Safe motherhood continues with planned pregnancies; early, quality prenatal care; knowledge of warning signs of problems; and the delivery of a healthy, full-term baby with the minimum of necessary interventions. Postpartum support for women and their families in a positive, nurturing environment also is important.

In 1998, in the United States, women can plan, carry, and deliver a pregnancy more safely than in the past. However, additional efforts need to be taken to make safe motherhood a reality for all women. Improved public health surveillance, prevention research, and prevention programs are needed to continue improving the health of women before, during, and after pregnancy and delivery. Examples include new surveillance methods to monitor and understand pregnancy complications; prevention research on the essential content of prenatal care; and prevention programs to ensure the adequate intake of folic acid by women of reproductive age to prevent neural tube defects (*3*).

The World Health Day Advisory Committee of the American Association for World Health coordinates World Health Day activities in the United States. Additional information about special events and resource materials about World Health Day 1998 are available from the American Association for World Health, 1825 K Street, N.W., Suite 1208, Washington, DC 20006; e-mail: AAWHstaff@aol.com; or from the World-Wide Web site: http://www.aawhworldhealth.org.

Statement of Mary Ann Waygan
March 18, 1999

Hello, my name is Mary Ann Waygan and I am the coordinator for the CDC Breast and Cervical Cancer Initiative for Cape Cod, Massachusetts.

Before I begin, I would like to thank Senators Chafee, Mikulski, Snowe and Moynihan for sponsoring this legislation. I would also like to thank Senator Smith for his support of this bill.

Clearly, the single largest problem facing the Breast and Cervical Cancer Screening Program today is finding resources and caregivers to provide treatment to the women who are diagnosed with breast or cervical cancer. The lack of treatment dollars is one of the biggest policy gaps in the program – and the problem is only getting worse.

The barriers to recruiting providers for charity care are growing, and funding for the treatment is an ad-hoc system that relies on volunteers, state workers and others to find treatment services. In the community, we go to tremendous ends to find treatment – and raise money to help pay for it. I've organized luncheons, bake sales, raffles – you name it. Anything to raise money for women who could not afford to pay out of pocket for treatment. Despite these efforts, all too often, we come up short.

Funding for treatment through the CDC program is the biggest problem I face as a coordinator and frankly a barrier to screening and detection. Funding for treatment is tenuous at best. Without passage of the Breast and Cervical Cancer Treatment Act, future funding for treatment for these women will remain uncertain.

I want to tell you one story in particular that clearly illustrates the problem some of these women face. A woman who lives in Buzzard's Bay, Massachusetts who was diagnosed with breast cancer through the CDC program.

Arlene McMann is a married woman in her early forties with two teenage sons and no health insurance.

When Arlene was diagnosed with breast cancer through the CDC screening program, she was devastated – not just with the diagnosis, but with the fact that she had no way to pay for the treatment she needed.

Faced with that situation, she and her husband were forced to use the $20,000 they had been saving for years to pay for their children's college tuition. In less than a year, that money was gone. After that, she and her husband were forced to go into debt to pay for her ongoing chemotherapy/radiation treatment and other procedures including a craniotomy and gall bladder surgery. They are now more than $40,000 in debt, were forced to move into a much smaller house and lost their dream of sending their sons to college without going into further debt.

The additional stress and pressure placed on Arlene and her husband by this situation has turned a difficult situation into an almost unbearable one. To make it even worse, Arlene recently found out that the cancer has spread to her hip, pelvis, lungs and liver.

Through all of this, Arlene has showed tremendous resolve. Despite being in pain and discomfort and forced to use a wheelchair, Arlene desperately wanted to be here today to share her story with you directly. She thought it was important for everyone to understand not just what the cancer had done to her, but what the affect of having to take on this incredible financial burden had done to her physical health, mental strength and family resources.

Due to her condition, Arlene's treatment finally is being paid because she qualified for disability. But to this day, Arlene is convinced that her cancer would not have spread had she been able to afford regular visits to an oncologist.

Arlene's energy and determination to fight this disease and remain positive are amazing. I feel lucky to know her and to have worked with her. I only wish that as the program coordinator, I could have done more – that I could have assured her that any treatment she needed would be paid for and that she wouldn't have to spend time dealing with bank statements, mortgages or packing boxes on top of everything else.

In summary, we hear over and over again that early detection saves lives. In actuality, early detection alone does nothing but find the disease; detection must be coupled with guaranteed, quality treatment to actually save lives.

We must pass the Breast and Cervical Cancer Treatment Act to make sure that screening and treatment always go together.

I would like to thank the National Breast Cancer Coalition for its leadership role in working to get this legislation passed and thank the members of Congress here today for sponsoring and supporting this legislation.

Thank you.

Jeb Bush
Governor

Robert G. Brooks, M.D.
Secretary

June 22 1999

The Honorable Connie Mack
United States Senate
517 Hart Senate Office Building
Washington DC 20510

Dear Senator Mack

This letter in response to the May 4th telephone inquiry from Mark Smith to Margo Blake regarding cancer treatment for women enrolled in Florida's Breast and Cervical Cancer Early Detection Program (the Program). Thank you for allowing us the opportunity to furnish some details about the Program.

Florida received its award from the Centers for Disease Control and Prevention (CDC) in late summer 1994. We started operations in nine counties in September 1995 and grew to 20 counties in 1998. The 20 counties are comprised of large urban areas, mid-sized counties and small rural counties. (A map depicting all 20 participating counties is enclosed.) Population data show that there are approximately 275,000 women, ages 50-64 in Florida who are under or uninsured. Slightly over 175,000 of these women reside in the 20 participating counties.

Since late 1995, CDC grant funds have allowed the Program to provide screening services to slightly over 10,000 eligible women. Annually, the participating counties screen approximately 3,500 women or about 2 percent of the eligible population. One hundred thirty women have been diagnosed with breast or invasive cervical cancer through this Program in Florida. As you know, CDC funds cover reimbursement at the Medicare rate, for breast and cervical screening services such as Pap smears and mammograms. There are also limited funds for specified diagnostic procedure such as colposcopies, biopsies, and breast ultrasounds. The CDC funds can not be used for reimbursement for treatment or other associated costs. This is the Program's most vulnerable area as we are now entering a competitive application process for additional CDC grant funds to begin year six in October 1999.

We are starting to see the strain our providers are experiencing through their support of the program. Before providing case scenarios that demonstrate this strain, I would like to expand on the definition of provider as used throughout this letter. Normally, we refer to the general or oncologic surgeon as the principal provider or treatment. Many others also donate services to the breast and cervical program. These include oncologists, radiologists, radiation oncologists, pathologists and hospitals.

The scenarios mentioned include the following:

- One county program worked with a client diagnosed with cervical cancer in November 1998. The woman saw a gynecological oncologist in January 1999 and underwent a hysterectomy in March after filing for Medicaid. Her family had to pay $6825 'up front' to cover hospital costs, which may be covered retroactively by Medicaid.

- One county program had three women diagnosed with breast cancer during their first two years in operation; each one cared for by a different provider. Since October 1998, five additional women have been diagnosed and approximately 10 to 15 more have abnormal clinical breast exam or mammogram results and could be diagnosed with cancer. Needless to say, the providers are concerned with these increasing numbers. Some of the providers have asked the local program coordinator not to refer additional patients to them for the remainder of this program year.

- Another county program has seen a total of 10 women with cancer and they have two to three physician providers and one hospital provider who agrees to see program clients. These providers have also expressed alarm at the number of women with abnormal exams who are referred to them for care. We have been told that these current providers may not be willing to support the Program when this county renews their program agreement this October.

- The fourth county program diagnosed 10 women with breast cancer during their first two years and since January 1998 diagnosed four more women with breast cancer. Ten providers who originally agreed to each see one to two clients per year have formed three separated groups who have agreed to see one to two clients per group, for a total of three to six clients per year. This would not be sufficient coverage if the rate of diagnosing cancer continues.

CDC has informally conveyed to us that they may award the Florida Program more funds for breast and cervical screening services in our next five-year grant cycle that begins this October. While this is positive news for the many thousands of women at need for these services, we also believe this will have a 'domino effect' on the providers who provide in-kind treatment. With increased numbers of women screened comes an increase in the numbers of cancers diagnosed, placing an ever-increasing burden on our already overwhelmed providers of cancer treatment! Please note these same providers more than likely also donate in-kind services to other clients diagnosed with cancer or other chronic diseases.

So while our information shows that a provider may furnish pro bono treatment for two or three women with breast or cervical cancer per year, in all likelihood that same provider is asked to donate treatment services for other clients as well. We are deeply indebted to all of these individuals and institutions for their support of the Program and would like to see them receive some measure of acknowledgement for their efforts.

In summary, the Florida Breast and Cervical Cancer Program has provided cancer services to over 10,000 women at or below the 200 percent poverty level, and found treatment services for over 130 women through the generosity of local providers in 20 counties. As screening numbers increase, so will the number of women diagnosed with breast or cervical cancer

Our providers are showing signs of abandoning this program unless we are able to provide them some assistance that is not available through the CDC grant.

Thank you for your personal interest in Florida's Program. If you have further questions, please feel free to contact me at (850) 487-2945, or Ms. Margo C. Blake, Program Manager for the Breast and Cervical Cancer Early Detection Program at (850) 488-2901. We look forward to a successful conclusion to this year's session and wish you our best.

Sincerely,

Robert G. Brooks, M.D.
Secretary, Department of Health

RGB/jg
Enclosure

Cc: Mark Smith

NATIONAL BREAST CANCER COALITION

« a grassroots advocacy effort »

Testimony of Fran Visco, President
National Breast Cancer Coalition
before the
House Commerce Committee
Subcommittee on Health and Environment
July 21, 1999

Thank you Mr. Chairman, and members of the Committee for inviting me to testify today. I am Fran Visco, President of the National Breast Cancer Coalition, and a breast cancer survivor. I am one of the 2.6 million women living with breast cancer in the U.S. today.

The National Breast Cancer Coalition (NBCC) is a grassroots advocacy organization dedicated to eradicating breast cancer. We are made up of 500 member organizations and more than 60,000 individual women, their families and friends. NBCC seeks to increase the influence of breast cancer survivors and other activists over public policy in cancer research, clinical trials, and access to quality health care for all women.

Background

The National Breast Cancer Coalition has made passage of H.R. 1070, the Breast and Cervical Cancer Treatment Act, a top priority. As you know, this legislation would establish a federal treatment component for the Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) that Congress enacted as part of the Breast and Cervical Cancer Mortality Prevention Act in 1990. That program – which has screened more than one-half a million women for breast cancer – does not provide any federal resources to pay for the treatment when women are diagnosed with breast or cervical cancer. Instead, Congress asks participating states to assure that the women who are screened get the treatment they need.

The fact that the CDC Early Detection Program does not cover any costs of treatment for breast and cervical cancer has created a very serious public policy gap. State and local providers and women themselves have been left to scramble for resources to pay for treatment. Women are relying on charity and donated care when it is available and sometimes going into debt when no public or private dollars can be found. The NBCCEDP is a program dedicated to serving low-income women, but at times fails to come through.

1707 L Street, NW, Suite 1060, Washington, DC 20036 phone: (202) 296-7477 fax: (202) 265-6854 http://www.natlbcc.org

Let me be perfectly clear. The individuals who run this program and the thousands of volunteers who help find women treatment do all that they can everyday to ensure that patients diagnosed through the program get the treatment they need. It is the people who do the screening and spend countless hours trying to find treatment who have identified the problems with a system that lacks a treatment component. It is the system that is broken, and we need to fix this problem so that they can screen more women, and not have to spend the majority of their time finding treatment services.

What H.R. 1070 Would Do

NBCC-Personal Stories

Not long after the CDC screening program was enacted into law, Jan Eick-Swigart, an NBCC advocate from California, launched an effort to guarantee treatment for women screened and diagnosed with breast cancer through the federal program.

Prior to losing her battle with breast cancer, Jan wrote a compelling memorandum on the need for a federal treatment component to CDC's Early Detection Program. Her memorandum states:

"One of the heartbreaking ironies about the BCCEDP and other programs that offer underserved women free or low cost mammography is the lack of resources to treat the women who are diagnosed with breast cancer as a result of these programs."

In the years following Jan Eick-Swigart's efforts to ensure that women screened and diagnosed with breast cancer through CDC's federal program are guaranteed treatment through Medicaid coverage, many NBCC advocates have reaffirmed the need for a federal treatment component to this program. Our members have witnessed the delay that can result from having to scramble to find treatment – and the physical and emotional result that delay has on women screened and diagnosed through the program.

A woman in Florida had to wait 5 months before a volunteer found her treatment dollars. This woman had five agonizing months of knowing she was sick and having no way to get the treatment she so desperately needed.

Moreover, we have heard from women who ultimately got treatment, but were then saddled with medical bills that they couldn't pay. Instead of focusing on getting well, these uninsured women have had to focus on how they are going pay for their care.

A woman in Massachusetts, for instance, has already spent her children's college fund for her treatment and is paying off more than $20,000 in medical bills. Her story is incorporated in a statement from Mary Ann Waygan, coordinator for the CDC Breast and Cervical Cancer Initiative for Cape Cod, Massachusetts. *(Mr. Speaker, may I introduce this statement into the record?)*

A woman in New York said that during her treatment, it seemed that her conversations with her doctors were more about the bills than how to save her life.

There are other women who after having a mammogram find out they need follow-up diagnostic services but refuse to get them. They do not want to know they have cancer without knowing exactly where the treatment dollars come from.

A woman from Virginia explained she "feels that if she is not diagnosed it is better because she will not have to worry about treatment."

A woman from Maine had an initial mammogram through the NBCCEDP program and the results were "highly suggestive of malignancy." Due to the cost, rather than pursue a biopsy and the treatment, which may have been needed, the client decided to wait and have a repeat mammogram in six months.

Surely, these scenarios are not what Congress intended when it enacted the National Breast and Cervical Cancer Early Detection Program into law. Yet, these scenarios are the reality of what happens when women are screened and diagnosed with breast and cervical cancer through a federal program that does not guarantee federal treatment coverage.

CDC-Case Study

NBCC is not alone in our belief that the CDC Early Detection Program needs a system that provides sufficient funding for treating women. In response to concerns about treatment raised across the country (and raised by advocates like us), CDC conducted a case study which illustrated a similar conclusion. The study focused on participating states (California, Michigan, Minnesota, New Mexico, New York, North Carolina and Texas) and looked at the treatment following a diagnosis of breast or cervical cancer through the program.

The results of that study, released in January 1998, found that although treatment had been initiated for most of the women in whom cancer was diagnosed, the system of treatment is "tenuous and fragile at best."

(Mr. Chairman, may I introduce the report which summarizes the results of the study into the record?)

The Numbers Don't Tell Us the Whole Story

I want to make very clear that the issue is not just that some women don't get treated. We have had to look beyond the numbers to find the real story. It is behind these numbers that the story exists – the story that women from all over the country come and talk to me about. It's the story that CDC's own study underscores. The story of women – diagnosed with breast and cervical cancer – wondering how and whether and when

they'll find treatment for their disease, and then often left with a lifetime of bills to pay for that treatment.

Lack of Treatment Funding Is Diverting Resources Away From the Screening Program

There are several findings that are very telling in the conclusions of CDC's study. First, the study highlights the considerable time and effort involved in developing and maintaining systems for diagnostic follow-up and treatment. It illustrates the labor-intensive process required to identify resources within states to provide diagnostic and treatment services.

NBCC has heard about the serious problems people who run the screening programs across the country have in finding treatment for women diagnosed through the program. The hours spent searching for treatment are diverting resources away from the screening program. As a result, fewer women are being screened. This is very serious - the program currently serves only 12% to 15% of age eligible, uninsured women nationally.

The threat that the lack of treatment funding poses – not only to the woman who have been diagnosed through the program – but also to the women who may rely on the screening services in the future – is lethal. **This** is the story behind the numbers.

It is our hope that in enacting a Medicaid option for these women, they will be presumed eligible for Medicaid on the first day that they are diagnosed. This way – they know they'll get the immediate care they need instead of facing delays and wondering how and whether they'll get treated. This way – program coordinators can focus their efforts on increasing the number of women they are able to screen for breast and cervical cancer.

In the Context of an Evolving Health Care System

Second, the CDC study puts this issue in the context of an evolving health care system. The study highlights what we too are hearing from our advocates around the country, and what Dr. Stanley Klausner has testified about today – an increasing number of physicians who do not have the autonomy, because of the changes in the health care system, to offer free or reduced-fee services to NBCCEDP clients.

Mr. Chairman, I point you to a letter from Robert Brooks, MD, Secretary of the Department of Health for the Florida Department of Health and Human Services.

(Mr. Chairman, may I submit this letter for the record?)

In his letter, Dr. Brooks writes, "We are starting to see the strain our providers are experiencing through their support of the program...One county program had had three women diagnosed with breast cancer during their first two years in operation; each one cared for by a different provider. Since October, 1998, five additional women have been diagnosed and approximately 10 to 15 more have abnormal clinical breast exam or

mammogram results and could be diagnosed with cancer. Needless to say, the providers are concerned with these increasing numbers. Some of the providers have asked the local program coordinator not to refer additional patients to them for the remainder of this program year..."

"...Another county program has seen a total of 10 women with cancer and they have two to three physician providers and one hospital provider who agrees to see program clients. Three providers have also expressed alarm at the number of women with abnormal exams who are referred to them for care. We have been told that these current providers may not be willing to support the Program when this county renews their program agreement this October..."

And the stories go on.

Dr. Brooks concludes with the fear that Florida's providers continue to show signs of abandoning this program unless they are provided with some assistance that is not available through the CDC grant.

Florida, a state with the highest degree of managed care penetration in the country, is perhaps one of the best (but certainly not the only) example of a situation where the lack of availability of treatment can only get worse, and where any attempts to expand the screening program are hindered.

It is important to note that as managed care continues to expand across the country, more and more doctors may have less autonomy to provide the charity care relied on by NBCCEDP coordinators. To illustrate this point, a recent survey based on 12,000 U.S. physicians was published in the April 1999 issue of the *Journal of the American Medical Association*. The study finds that doctors whose income depends most heavily on health maintenance organizations and other managed-care health plans, on average, devote only half as much time to charity care as do their colleagues who don't participate in managed care.

What will this mean for the people who run the NBCCEDP programs who are already spending countless hours searching for treatment for women diagnosed with breast and cervical cancer? What will this mean for women who are already suffering a delay in treatment? Or who are saddled with treatment bills they can't pay? Or who are reluctant to get screened because they "prefer not to know" if there is no treatment available?

What will this mean for the ability of the National Breast and Cervical Cancer Early Detection Program to sustain itself?

Precedent in the Medicaid Program

Respondents in CDC's study suggest a similar solution to the lack of funding for treatment that we bring before you today – a solution that passage of H.R. 1070 would guarantee. That solution is a provision of treatment services assured through a federal

"Medicaid option" which would give state Medicaid programs permission to allow eligibility to BCCEDP clients who are diagnosed with cancer through the program. This would include those women who are eligible for BCCEDP services but whose incomes and/or assets exceed Medicaid limits.

There is a precedent for covering participants in the Breast and Cervical Cancer Early Detection Program under Medicaid. In 1993, Congress created the Tuberculosis Optional Benefit Program, making individuals who are infected with tuberculosis eligible for Medicaid.

Mr. Chairman, and Members of the Committee, as the stories of NBCC's advocates and as the results of CDC's own study show – what we have today is an ad-hoc system that is incapable of serving the future needs of the program and the women it serves. Solutions in the vast majority of states are short-term, tenuous and fragile. The fact that so many women eventually get treated reflects the dedication of providers and volunteers who spend enormous effort and time to find treatment services. Yet, while the majority of women get care, there is no system of care. As a result, some women experience unnecessary delays or are lost to follow-up care, and a few don't get treated at all.

Our message is not to put an end to the screening program. It is to finish the work Congress initiated in 1990 by adopting a treatment component that will serve all the women screened and diagnosed with breast and cervical cancer through this program.

How This New Treatment Program Would Work

Enactment of H.R. 1070 would allow the women who are eligible for the CDC Early Detection program -- that is women who are between 200% and 250% of poverty depending on their state and who are not already insured -- to receive their treatment through the state Medicaid program. States would not be required to participate, but those that do will receive an enhanced match – 75 percent federal dollars and 25 percent state dollars.

NBCC is heartened by the incredible support for this legislation from you, Mr. Chairman, and from the Committee. All but three Subcommittee members have signed on as cosponsors, and three quarters of the Full Commerce Committee has cosponsored H.R. 1070. We are pleased that in a bipartisan way – this Committee has come together in recognition that breast and cervical cancer screening alone does not prevent cancer deaths; it must be coupled with treatment if we are to achieve a reduction in mortality.

We now ask the Committee to ensure that happens as the screening program grows by enacting H.R. 1070, the Breast and Cervical Cancer Treatment Act this Congress.

Mr. Chairman, and members of the Committee, thank you again for the opportunity to testify. We look forward to working with you on this critically important issue. I'd be happy to answer any questions you may have.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

TESTIMONY OF

NANCY C. LEE, M.D.

DIRECTOR

DIVISION OF CANCER PREVENTION AND CONTROL

NATIONAL CENTER FOR CHRONIC DISEASE

PREVENTION AND HEALTH PROMOTION

CENTERS FOR DISEASE CONTROL AND PREVENTION

DEPARTMENT OF HEALTH AND HUMAN SERVICES

before the

SUBCOMMITTEE ON HEALTH AND ENVIRONMENT

COMMITTEE ON COMMERCE

U.S. HOUSE OF REPRESENTATIVES

July 21, 1999

Good Morning. I am Dr. Nancy Lee, Director of the Division of Cancer Prevention and Control of the National Centers for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC). I am pleased to be here this morning to discuss CDC's National Breast and Cervical Cancer Early Detection Program.

Recognizing the value of appropriate cancer screening, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990 (Public Law 101-354). CDC is in the ninth year of the National Breast and Cervical Cancer Early Detection Program, which brings critical breast and cervical cancer screening services to underserved women, including older women, women with low incomes, and women of racial and ethnic minorities. While successes and advances have been made with the help of this program, challenges still exist.

CDC supports early detection programs in all 50 states, five U.S. territories, the District of Columbia, and 15 American Indian and Alaska Native organizations. The program establishes, expands, and improves community-based screening services for women to reduce breast and cervical cancer mortality. The success of the breast and cervical cancer program depends on screening, education and outreach, partnership development, case management, and mechanisms to assure the quality of tests and procedures.

Through September of 1998, more than 2 million screening tests have been provided to over 1.3 million women. That number includes 1 million Pap tests and 950,000 mammograms. Almost half of these screenings were to minority women, who have traditionally had less access to these

services. Over 5,000 women have been diagnosed with breast cancer, more than 30,000 women were diagnosed with precancerous cervical lesions, and 411 women had invasive cervical cancer.

CDC collects data from all funded programs to monitor and evaluate each program's provision of clinical services. For each woman enrolled in the program, information is collected on demographic characteristics, results from mammograms, breast exams, and Pap tests, diagnostic procedures and outcomes, cancer diagnoses, and for women diagnosed with cancer, whether treatment was initiated.

The program's success is due in part, from a large network of professionals, coalitions and national organizations dedicated to the early detection of breast and cervical cancer.

- An estimated 27,000 health professionals are involved in providing breast and cervical cancer screening services to underserved women.
- More than 18,000 health educators and outreach workers are educating women on the importance of early detection and helping them access critical screening and follow-up services.
- More than 7,000 individuals are now members of a national network of coalitions that have joined together with State health departments in support of this program.
- One of CDC's partners in the program, Avon, has raised more than $32 million in additional dollars to educate women about breast cancer and to provide underserved women with access to early detection services.

There has been a 20 percent increase in screening mammography rates among all women 50 years and older since 1991, when the program was formally established. For both mammograms and Pap tests, the disparity rates for most of the minority groups have either been eliminated or reduced. There has been a recent decline in the rate of breast cancer mortality. And while there remains much to be done, our most recent mortality data from 1996 indicates that we have met the Healthy People 2000 goal of reduced mortality from breast cancer.

Insuring that all women with abnormal screening results receive adequate follow-up and a definitive diagnosis is a crucial component of this program. Thus, breast diagnostic services funded by federal dollars include diagnostic mammography, breast ultrasound, fine needle aspiration and breast biopsy and for the cervix, colposcopy and colposcopy-directed biopsy.

The legislation that authorizes the National Program does not allow federal resources appropriated for the program to be used for treatment. However, States are required, under terms of the grants they receive, to assure that women who are screened and need cancer treatment, receive care.

Data through March 1998 show that 92 percent of the women diagnosed with breast cancer and invasive cervical cancer have initiated treatment. The rest refused treatment, have not yet initiated treatment, or are lost to follow-up. For women diagnosed with breast cancer, data show a median of 8 days between the cancer diagnosis and the initiation of treatment.

A detailed study of seven state screening programs conducted by Battelle Centers for Public Health Research and Evaluation and the University of Michigan, funded by the CDC, documents the innovative approaches that have been implemented to identify and secure resources for treatment services. The study confirmed what we see in our Program data that arrangements for treatment were made for almost all clients who received a diagnosis of breast or cervical cancer. States' efforts to secure treatment for women screened through the Program have been further documented in a separate study conducted by the Susan G. Komen Breast Cancer Foundation.

State programs and their partners have invested significant amounts of time and effort to develop systems of care for diagnostic follow-up and treatment; these systems appear to be working. However, tremendous effort is involved in developing, implementing, and maintaining strategies and systems for these services. Rarely is there a standardized way that a State, tribe or territory obtains treatment services women need that are not covered by the program. Efforts typically are tailored to an individual client's needs and resources.

State programs have developed sophisticated, creative and successful strategies to deal with the tremendous challenge of payment for cancer treatment. The following are some of the strategies that are employed by States to secure treatment services for women:

- Providers assist eligible clients in applying for Medicaid, Hill Burton funds, or other types of public assistance.
- Clients may be referred to public hospitals, or receive care though hospital community benefit programs, donated services, or other charitable care.

- Contracts with screening providers require that agreements with treatment providers be established before screening commences.
- The Program appeals to treatment providers, through state and county medical societies and professional associations, to offer free or reduced-cost services to program clients.

Case management was identified in the Battelle study as one strategy that could assist programs in their efforts to ensure the follow-up and treatment of clients. CDC has developed a comprehensive policy on case management for the program. Increases in CDC's FY 1999 appropriation will be used to expand critical case management services in States that strengthen the fragile system for securing treatment services. With these funds, each program will enhance case management activities to assist clients navigate through the system to obtain treatment services that are not covered by the program.

Both North Carolina and Arkansas have appropriated State resources to the Cancer Control Programs to provide for cancer diagnostic and treatment services for all state citizens who meet eligibility criteria. California utilized a one-time allocation of $12.8 million from the Blue Cross Foundation to create a Breast Cancer Treatment Fund, which paid for treatment during the first year after diagnosis for any uninsured California women who met eligibility requirements. Unfortunately, this fund is nearly depleted.

Although States are currently meeting their commitment to help women access treatment services, several of the programs reviewed in the Battelle study expressed concerns regarding their ability to expand screening services to more women in need because the systems in place

for obtaining charitable treatment are becoming overburdened. These programs stated that as long as the numbers of cancers diagnosed through the program remain near the current level, the burden should not be too great or too threatening.

However, increased screening -- which is our goal -- is accompanied by increased numbers of cancers diagnosed, and many physicians who contract with programs are concerned about bringing more uninsured patients into their care, because of the need to provide treatment. Lack of sources for treatment can lead to screening problems in states where screening providers must have standing treatment referral options in order to screen.

States are finding it more and more challenging to ensure that these women get the treatment they need. The labor-intensive and piecemeal approach needed to secure treatment services diverts human and financial resources away from the screening services. The overall goal of this program is to reduce mortality from breast and cervical cancers, and the success of this effort hinges on the identification and treatment of early stage cancers and precancers. As they have in the past, CDC and its state partners will continue to give priority to this critical aspect of the early detection effort.

Let me relay to you how one woman felt about the program:

I was forty years of age, a recently divorced women with no health insurance and working for peanuts when I discovered a lump in my breast. It was a very traumatic experience, to say the least. My fears that accompanied this finding were overwhelming. In my present financial position, I would have never received the medical attention I needed, if it wasn't for your program. I am healthy, the lump was benign. Through this entire ordeal, I was able to focus all my energies on my medical problem, while your office proficiently attended the bills.

CDC's National Breast and Cervical Cancer Early Detection Program does not change whether or not a women has cancer. However, it can help women by improving their chances of detecting cancer earlier and getting treatment for it. And by finding and treating precancerous cervical lesions, the Program prevents thousands of women from ever developing cervical cancer.

Thank you, and I would be happy to answer any questions you may have.

The Susan G. Komen
Breast Cancer Foundation
National Headquarters

STATEMENT OF

SUSAN BRAUN

PRESIDENT & CHIEF EXECUTIVE OFFICER

OF

THE SUSAN G. KOMEN BREAST CANCER FOUNDATION

BEFORE THE

SUBCOMMITTEE ON HEALTH AND ENVIRONMENT
COMMITTEE ON COMMERCE

JULY 21, 1999

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Helpline 1.800 I'M AWARE (1.800.462.9273)

Ensuring Breast Cancer Treatment among Uninsured Women

Statement before the House Commerce Committee:

Subcommittee on Health and the Environment

Hearing: July 21, 1999

Good morning Chairman Bilirakis and members of the Committee:

It is an honor to be offered the opportunity to speak before you today about the pressing issue of treating uninsured women with breast cancer.

My name is Susan Braun, and I am president and chief executive officer of the Susan G. Komen Breast Cancer Foundation. The Komen Foundation was established 17 years ago by Nancy Brinker, in honor of her sister, Suzy Komen, who died of breast cancer at the age of 36. Our mission is to eradicate breast cancer by advancing research, education, screening, and treatment. To date, we have raised and spent more than $200 million toward this end. Our network of 106 Affiliates in 43 states and the District of Columbia, and the 35,000 volunteers that support them are conducting 98 Komen Race for the Cure® events this year. Last year, through the Race series and other fund-raising vehicles, we raised nearly $80 million.

It is not to pat ourselves on the back that I share with you these figures. Rather, it is to help illustrate to you the reach of the Komen Foundation and to demonstrate that "grass roots" is a way of being for us, not a mere cliché. Further, it is to establish the level of trust that we have earned with the public -- trust that allows them to put a large sum of money in our hands with the assurance that it will be spent wisely in pursuit of our mission to eradicate breast cancer. We cherish that trust and work tirelessly to remain worthy.
Komen affiliates work at the local level to build the public awareness of breast cancer and to establish the best settings possible for education and early

detection. At a national level, we continue to establish programs to support our affiliates in these endeavors. In addition, we are (according to the Institute of Medicine) the largest private funder of research dedicated exclusively to breast cancer. Last year we funded 79 basic, clinical, and translational research grants, with grantees selected through a novel and well-respected blinded peer-review program. In addition we funded population-specific studies and post-doctoral fellows from our national grants fund for a total of over $17 million. Our affiliates granted another $25 million to local programs.

Again, I describe this program not as a means of touting the successes of the Komen Foundation. Rather, I wish to underscore also that we are quite experienced as funders of novel and strong programs. We investigate our areas of spending in significant depth, ensuring that we are serving the public trust that has been placed in us. It is with this backdrop that we began to study the issue of treatment for underserved women over a year ago.

Statement of the Problem:

An estimated 175,000 new cases of breast cancer will be diagnosed in 1999 and 43,300 women will die of the disease. Despite promising new prevention treatments, finding and treating cancers in their earliest stage remains our most effective way of reducing the morbidity and mortality associated with this disease.

The good news is that an increasing number of women are receiving mammograms. In 1995, over 80 percent of women 40 years of age and over reported ever having had a mammogram and about 60 percent reported having had a mammogram and clinical breast exam within the past 2 years. The National Breast and Cervical Cancer Early Detection Program (NBCCEDP), operated by the Centers for Disease Control and Prevention (CDC), has played a critical role in this achievement, ensuring that low income, underinsured and uninsured women are not left out of the success story. The NBCCEDP has

provided almost three-quarters of a million mammograms to low-income, underinsured and uninsured women.

However, while the past decade has been witness to significant increases in the utilization of early detection services for breast and cervical cancer, we are now challenged to ensure access to necessary diagnostic and treatment services for women whose mammogram or Pap test yields suspicious findings.

In working to assess how to best go about ensuring accurate diagnosis and appropriate treatment of breast cancer, we have established the following basic premises:

- Women diagnosed with breast cancer *must* be treated if they so choose, irrespective of their ability to pay.

- The quality of treatment they receive should be the highest possible.

- The time between diagnosis and initiation of treatment must be as short as possible.

- Care should be coordinated, ensuring the best care by the correct specialist.

- Care must not be short-term only; follow-up for at least five years is required.

Upon establishing these central tenets, we then explored the critical questions that needed to be answered in order to provide timely, coordinated, comprehensive, and high-quality treatment to uninsured women. This led to four key questions:

Question One: What is the magnitude of need?

Our very general estimates indicated that the potential magnitude of need is significant. As you can see in the chart attached to the following page, there are an estimated 1,000 women screened through the BCCEDP program each year who may require treatment assistance. In addition, there are an estimated 20,000 women who are eligible for BCCEDP but are not presently being screened, who are likely to develop breast cancer, and have no access to this program and what it offers in terms of diagnostic services and case management for further care.

ESTIMATED ANNUAL NUMBER OF WOMEN IN THE US IN NEED OF FINANCIAL ASSISTANCE FOR THE TREATMENT OF BREAST CANCER

51,000,000	# of women ages 35-64 in the U.S. within screening range, ineligible (by age only) for Medicare
X .16	Percent uninsured
8,160,000	# of uninsured women in the U.S., ages 35-64
X .0029	Annual diagnosis rate, ages 35-64
23,664	**# of uninsured women, ages 35-64, potentially diagnosed with breast cancer each year**

23,664	**# of uninsured women, ages 35-64, potentially diagnosed with breast cancer each year**		**23,664**
X .15	Percent of women reached by the NBCCEDP	Percent of women not reached by the NBCCEDP	X .85
3,550	Potential number screened and diagnosed annually by NBCCEDP	Potential number not screened/diagnosed through NBCCEDP	20,114
X .05	Percent not initiating treatment	Percent not initiating treatment	X 1.00
178	**Number of women with no treatment**	**Number of women with no screening or treatment**	**20,114**
3,372	Potential number screened and diagnosed annually by NBCCEDP who will initiate treatment	Potential number not screened/diagnosed through NBCCEDP	20,114
X .25	Estimated percent enrolled in NBCCEDP paying out-of-pocket		
843	Number of women screened and diagnosed through NBCCEDP who may need treatment assistance (excluding the 5% not initiating treatment)		
1,021	**Estimated number of women needing treatment assistance (women not currently getting treatment or those who are receiving treatment but may need additional financial assistance) [843 + 178]**	**Estimated number of women needing financial assistance for breast cancer treatment**	**20,114**

Notes: This model is based on simple estimates to begin the process of determining the magnitude of need and where the need exists. The model is for breast cancer only. The number of unemployed is likely an overstatement of the true NBCCEDP reach; thus total number of treatment may be a high estimate.

Question Two: In which populations does the need for treatment assistance lie?

The need for treatment assistance for women diagnosed with breast cancer lies primarily among the uninsured, medically needy, and/or underserved. In addition, insured women who have lost their coverage or have reached a lifetime maximum, particularly those being treated for a recurrence of their breast cancer, can be in need. Women with healthcare coverage but with a policy that excludes some forms of treatment may also be at need.

Question Three: What can be done to meet the needs for treatment for those screened and diagnosed through the BCCCEDP and those not reached at all through the program?

Reaching women who have been screened and diagnosed through the BCCEDP with treatment assistance is more straightforward than reaching those who are not. Those who have been diagnosed within the program can be assisted by case managers, who will help find available services or a program that can provide special national, state, or local funds. Eight states have legislated breast cancer treatment funds, and local programs (such as "The Bridge" in Dallas) also exist. Pro-bono care is provided in many communities. In the case of failure of these funding options, federal assistance may be required.

To reach those women who are eligible for but unscreened by the BCCEDP, more outreach must be undertaken to ensure detection of breast cancer as early as possible to improve the likelihood of a favorable outcome. At present, due to lack of interaction with the healthcare system, these women may not be diagnosed at all, or may appear in emergency rooms or public clinics with advanced disease. For this group to be assured that early screening and diagnosis will be achieved, CDC program funding will require regular increases.

Question 4: What are potential models for meeting the needs of those diagnosed?

Recognizing the growing need for additional information about the provision of breast cancer diagnostic and treatment services among women who have no means of support for such services, and in order to guide our actions as a funder of treatment assistance programs, the Susan G. Komen Breast Cancer Foundation initiated a study. It covered current strategies being used by communities across the country to address the growing challenge of ensuring diagnostic and treatment services. This study, which I am now introducing into the record, revealed:

- Women are receiving treatment. Both the CDC and the Komen Foundation studies found that treatment was initiated for the vast majority of women who received a diagnosis of breast cancer. While imperfect and needing further resources, the system has been providing treatment for most women who need and want it.

- Patient navigator and case management services are critical in ensuring follow-up diagnostic and treatment services for women with suspicious screening findings. Case managers determine patient eligibility for assistance programs, including Medicaid and Medicare, identify and negotiate alternative sources of donated care, identify and coordinate provision of support service needs, such as transportation and child care, and assist women in understanding and navigating an increasingly complex health care system. Such services are critical even in areas that have treatment funds and will continue to be necessary if states have an option to provide for treatment services under Medicaid.

- Provision of services reflects a delicate web of relationships and linkages across public and private organizations and across the federal, state, and

local levels. Local communities are meeting the challenge of ensuring treatment services through the dedication of local health care and community professionals who donate services.

- The need for early detection services exceeds current levels of support. While the NBCCEDP has reached more than 1.3 million women with screening services, this represents only 12-15 percent of the women eligible for services in each state. Currently, state awards under the NBCCEDP range from $1.0 million to $5.0 million annually based on state population, the number of uninsured and underinsured low-income women, state capacity, and other factors. The need for early detection services outweighs current levels of support. Some partnerships between public and private organizations have been established to address the need for educational outreach and screening. Examples include the ENCOREplus program in St. Joseph, Missouri, which addresses barriers women face to health education and access to education and detection services and the Montana Department of Public Health and Human Services screening program.

- Innovative partnerships are being formed to address local treatment needs. Our study identified ten treatment funds established specifically to meet the needs of low-income uninsured and underinsured women. These included three privately funded (California Treatment Fund, Orange County Susan G. Komen Breast Cancer Foundation, and South Dakota Women's Cancer Network) and seven state-funded programs (Arkansas, Georgia, Rhode Island, Maryland, North Carolina, South Carolina, West Virginia). These initiatives varied considerably in sources of support, structure, services covered, size and other important factors. They combined the unique local strengths of public and private sector partners and all were tailored to local circumstances. These local solutions

generally are the result of partnerships between the government and private sector.

Actions for Success

Efforts to meet the challenge of ensuring early detection and treatment for breast and cervical cancer over the past decade have yielded both successes and lessons. Many women are being diagnosed and treated, case management is critical to ensuring this treatment, the current local infrastructure for ensuring treatment reflects a delicate web of services and relationships, current funding is insufficient to fully address the magnitude of need, and innovative public/private partnerships hold the promise of meeting these challenges for the long-term future.

Potential models for meeting the needs of those being diagnosed include:

- *Community treatment models: Expand case management and public/private funds to strengthen and expand existing models.*

- *State treatment plans, which currently exist in some states: Model state legislation for treatment programs with federal demonstration project monies.*

- *Establish a Ryan White type program, which is used for HIV treatment.*

- *Use or enhance existing provisions with respect to state medical necessity provisions under Medicaid.*

- *Establish a Medicare adjunct program with a separate funding base.*

- *Other comprehensive programs.*

We realize that the purpose of today's hearing is to discuss H.R. 1070, a bill to amend Title XIX of the Social Security Act to provide medical assistance for women screened and found to have breast or cervical cancer under the BCCEDP program. We highly credit Congressman Lazio and Congresswoman Eshoo for championing this plan and being true allies in the fight against breast cancer.

As stated previously, Medicaid assistance is one of several options for dealing with the needs of uninsured, low income women who are treated for breast cancer. Contrary to some accounts we have heard, the Komen Foundation is not opposed to this legislation. We are concerned, however, that any treatment initiative provides a comprehensive and effective solution and reaches those most in need of assistance. Therefore, if serious consideration is to be given to this alternative, as opposed to others, we urge consideration of the following points:

- Medicaid participation is optional in the proposed bill. States with limited funds in their Medicaid program may be reluctant to cover care for people who would otherwise be ineligible.

- Medicaid programs may be adverse to participate in an optional program that is diagnosis-specific (that is, only targeted for one disease). Although the mission of the Komen Foundation is focused only on breast cancer, we are aware of the needs of many people with other diseases who are covered by Medicaid.

- Medicaid varies considerably from state to state. Some states can afford more care than others can. An optional program that requires an initial investment on the part of states may be "picked up" only by the wealthier states. This may contribute to the variation in how a woman may be treated

in one state compared to another.

- Eligibility for a Medicaid program may require women to spend down their resources before they qualify, and it is important that the financial status of patients undergoing treatment not be jeopardized.

- Medicaid eligibility only for women who are screened through the BCCEDP program does not account for the 85% of women who are eligible for the program but not reached. A certain percentage of these women, who may not be in touch with any healthcare services at all, will nonetheless develop breast cancer.

- Follow-up for breast cancer is standardly provided for at least five years following treatment. Any program that is medically sound must also provide for follow up.

It is critical that any proposed treatment strategy address the full audience and the long-term issues associated with breast cancer treatment. Treatment of breast cancer is required by all who have the disease and wish to be treated, irrespective of where they were screened or where their disease was diagnosed. Women treated must be followed up to ensure the best possible outcomes. This issue is of grave concern to all involved with breast cancer. We must ensure a comprehensive solution, lest we walk away prematurely, with the notion that we have "solved the problem." We are indeed running quickly up this very important ladder; let us be certain that we have it propped against the appropriate building.

Thank you very much for your time and attention.

Testimony of

Stanley Klausner, MD, FACS

On Behalf of H.R 1070, a Bill to Amend Title XIX of the Social Security Act.

Submitted to Committee on Commerce

U.S. House of Representatives

July 21, 1999

My name is Dr. Stanley Klausner and I am a board certified General Surgeon specializing in the treatment of diseases of the breast. I live and practice on Long Island where breast cancer is extremely prevalent. During my 25 years in practice, I became focused on treatment of breast cancer, a disease which attacks one in eight women. I am currently the Director of Breast Services at Brookhaven Memorial Hospital in Patchogue New York, a medium sized community hospital located on Suffolk County's south shore. I maintain a busy private practice devoted almost exclusively to breast disease and run a weekly breast clinic at two Health Centers in Suffolk County.

I recently learned of Congressman Lazio's bill H.R. 1070 to amend Title XIX of the Social Security Act to provide medical assistance for certain women screened and found to have breast or cervical cancer under a federally funded screening program. I am compelled to speak to you in support of its enactment. I am not here representing any political or special interest group. Rather, I speak to you as a "hands on" community doctor and want to tell you my experiences in treating the population addressed by this bill, a population called the "working poor".

In 1995 I became aware of a growing need to treat the working poor in my community who were unable to obtain comprehensive breast care at a local level. These patients were being seen by primary care physicians in the private sector and at the County Health Centers. When a diagnosis of breast cancer was made (often through the National Breast and Cervical Cancer Early Detection Program or NBCCEDP) they were being referred to a tertiary care facility such as Stony Brook

University Hospital. There they worked their way through the system trying to obtain treatment. Unfortunately, the care of breast cancer patients is multifaceted and many patients often obtained inconsistent levels of care. At that time, I was asked by the administrator of the South Brookhaven Health Center in Patchogue to set up a program for the **total care of patients with breast disease.** He would in turn attempt to fund the program through the County. My task, besides developing the mechanics of a breast clinic, was to assemble a group of volunteer specialists willing to treat these patients, often for free. Problems abounded especially when physician's services required durable medical supplies or drugs. This problem still exists. We were able to prevail and the program is quite successful. I have attached an abstract of the 1998 statistics from the Health Center for your consideration labeled **Exhibit A.** It provides you with percentages of breast cancer in our sampling population. It also lists the patient's financial class. You will note in the exhibit, 59% of our patients were uninsured. When I started the program in 1995 that percentage was 33%.

I previously alluded to the treatment of breast cancer as multifaceted. It is important for you to understand the many services needed to treat this disease and the costs they represent to the working poor. Once a diagnosis of breast cancer is made, the following services may be required (depending on the type and severity of the tumor):

- **Breast Surgeon** to perform either a mastectomy or a breast sparing surgical procedure such as a lumpectomy and axillary lymph node dissection.

- **Medical oncologist** to provide chemotherary and hormonal therapy.
- **Radiation oncologist** to provide radiotherapy.
- **Plastic surgeon** to provide reconstruction to the mastectomy site.
- **Prosthetics** for the patient to use if reconstruction is not done.
- **Psychological** counseling.
- Various **support groups**.

These services are in addition to the more mundane ones such as **pathology, laboratory, in-hospital services and even pain medications.** All of these modalities must be in place in order to provide "**standard of care**" for the breast cancer patient. Having only a part of these services funded, while somehow believing the patient can pay for the others, is unrealistic.

Over the years that my breast program has been in effect, a disturbing trend has been emerging. With the advent and penetration of **managed care**, physicians are faced with new challenges. They must see higher volume in order to maintain an acceptable bottom line. The "**free services**" they render to the working poor are straining their ability to adapt and is making the breast program more difficult to implement. I fear that in the near future the altruistic feelings of my fellow physicians may be supplanted by the adage "charity begins at home."

Even more disturbing is my gradual awareness that the **working poor are afraid to elect breast conserving surgery**. They are so terrified of medical bills that their medical judgement is biased. Take for example a working mother supporting two children and not qualified for medicaid. Even if her breast cancer is amenable to breast conserving surgery, she often elects a mastectomy because she knows the cost of the

additional treatments needed in breast conservation, such as radiation and chemotherapy, are too expensive. What a difficult decision this woman must make when she opts to sacrifice her breast rather than incur medical bills she can't pay. As for plastic surgical reconstruction of her mastectomy site, this has simply never been an option.

I can continue giving you my personal experiences in treating the working poor and tell you of the courage and dignity most all have shown. Unfortunately it would take considerably more than my allotted time. Most simply put, these patients have been thrust into the healthcare arena through no fault of their own. They know they can't pay for expensive treatments yet they must "work the system" in order to survive. Every one of us has a cause we support. We all love to rally for a wrong that needs to be made right. **Mine is to continue to be able to treat this disease in** all **of my patients.** My being here today is to urge you, the Congress of the United States, to provide some economic support to ease the hard choices the working poor must make and to help the system accommodate their care. I firmly believe enacting H.R.1070 gives the Congress an opportunity to improve the outcomes of the working poor afflicted with breast cancer. You wisely legislated funds for diagnosis, now I urge you to complete the job by funding treatment as well.

I thank you for your attention.

Exhibit A

The following is the statistical summary for the Breast Disease Program in 1998:

Patient visits:	534
Diagnostic procedures	113
Surgery	
mastectomy/resection	21
Other cancer treatment	6
Financial Class	
Self Pay	59%
Medicaid	29%
Medicare	9%
Private Insurance	3