S. HRG. 106–215

MEDICAL ASSISTANCE FOR CERTAIN WOMEN FOUND TO HAVE BREAST OR CERVICAL CANCER

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH CARE

OF THE

COMMITTEE ON FINANCE

UNITED STATES SENATE

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FIRST SESSION

ON

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MEDICAL ASSISTANCE FOR CERTAIN WOMEN FOUND TO HAVE BREAST OR CERVICAL CANCER

TUESDAY, JULY 27, 1999

U.S. SENATE,
SUBCOMMITTEE ON HEALTH CARE,
COMMITTEE ON FINANCE,
Washington, DC.

The meeting was convened, pursuant to notice, at 2:30 p.m., in room SD–215, Dirksen Senate Office Building, Hon. John H. Chafee (chairman of the subcommittee) presiding.

Also present: Senator Bryan.

OPENING STATEMENT OF HON. JOHN H. CHAFEE, A U.S. SENATOR FROM RHODE ISLAND

Senator CHAFEE. I want to welcome everybody here this afternoon. This is the Subcommittee on Health Care of the Finance Committee. And we are delighted that we have so many witnesses here today. And the way we are going to do it, we will have the two panels. The first panel will have Hon. Barbara Mikulski of Maryland as the witness. And then following that, we will have the second group of witnesses.

In connection with the start, I would like to introduce into the record a statement by Senator Olympia Snowe from Maine and a statement by Senator Bob Graham of Florida, both on this subject. Both of these Senators have been actively involved in seeking cures and taking care of those with breast cancer. And we are delighted to have their statements.

[The prepared statements of Senators Snowe and Graham appear in the appendix.]

Senator CHAFEE. In 1990, Congress took an important step to fight breast and cervical cancer by passing the Breast and Cervical Cancer Mortality Prevention Act. That was nearly 10 years ago. This law authorized a breast and cervical cancer screening program for low-income, uninsured, or under-insured women through the Center for Disease Control.

I support those efforts and applaud the important work of CDC and its screening programs across the country for if breast cancer is detected and treated early, the 5-year survival rate is an astonishing 97 percent. I think it is important for all us to remember that if breast cancer is detected and treated early, the 5-year survival rate is an astounding 97 percent.

But diagnosis without treatment is only half the battle against breast cancer. In fact, it is tantamount to doing nothing. To be sure, the ultimate goal of the Center for Disease Control Screening Program is, namely, to decrease the mortality rate from breast and cervical cancer among American women.

Yet, as we will hear today, despite CDC's concerted efforts to locate treatment for these women, due to circumstances beyond their control, optimal care is not always available.

Consequently, the treatment these women receive is sometimes delayed or incomplete or may leave many of them with large medical bills they cannot pay. In the worse scenario, some women receive no treatment at all.

While these patients are all poor, they are not eligible for Medicaid because their income is either too high or they do not fit into the program's eligibility categories. None are old enough to qualify for Medicare.

Let us remember, the statistics on poverty expose a great disparity between the national poverty rate and the eligibility rate for Medicaid. Although a family of three earning less than $15,650 per year lives below the national poverty rate. On average, only those families with an annual income below $9,500 qualify for Medicaid.

Now, there is a hitch. People say, well, are these women already on Medicaid? What is the problem? No. The answer is just because they are lower than the national poverty rate does not mean they are on Medicaid. The Medicare amount is much lower than that.

In some States, this figure is much lower. In Alabama, for example, only those families with an annual income of less than $3,600 qualify for Medicaid.

Apparently, a gaping hole exists in the current program. I simply cannot understand why we in government spend good money on a program to diagnose women with cancer only to tell them we cannot help them find adequate treatment. Why do we do anything at all? Surely, leaving these women with a diagnosis of a life-threatening disease and nowhere to turn seems to me to be worse than detecting the cancer.

I believe we can do better. That is why I was proud to join Senators Mikulski, Snowe, Gordon, Smith, and others in introducing the Breast and Cervical Cancer Treatment Act in March. This modest bill would give States the option to provide these women diagnosed with breast or cervical cancer under CDC's screening program, many of whom are mothers of young children, with treatment through the Medicaid program.

Mind you, this is optional. This does not require the States to do anything. If a State does not want to do it, then they do not have to do it, but this gives them the opportunity to do it using Medicaid.

And obviously, in Medicaid, the Federal Government is in for basically one-half while the States are in for the other half. The coverage would continue until the treatment and follow-up visits are completed, typically 5 years.

Compared to the large Federal outlay for other public health programs, this bill only costs $315 million over 5 years. It is targeted to a small population.

Since the program's inception less than a decade ago, only 3,600 women have been diagnosed with breast cancer and 400 with cervical cancer. And some, only a handful of women nationwide would be eligible for Medicaid under this legislation.

Although small, this bill makes all the difference in the world in the lives of low-income and uninsured women with breast and cervical cancer. I believe we should finish the job we started in 1990 by filling in this critical gap in a vital Federal program. So I look forward to the testimony we will hear this afternoon.

And Senator Mikulski, I know you have long been interested in this subject. And your work has been outstanding. And we look forward to your testimony. So would you please proceed?

STATEMENT OF HON. BARBARA A. MIKULSKI, A U.S. SENATOR FROM MARYLAND

Senator MIKULSKI. Thank you very much, Senator Chafee. I am going to ask unanimous consent that my full statement be included in the record.

Senator CHAFEE. Fine.

[The prepared statement of Senator Mikulski appears in the appendix.]

Senator MIKULSKI. I want to thank you for your gracious invitation to testify on this legislation. And I wanted to come and testify for two reasons. First, I wanted to come to be here and in a public forum with a very crucial issue affecting women's health. I wanted to personally thank you for your leadership, your support, and your advocacy on this issue.

When I first came to the Senate in 1987, I was the only Democratic woman here. I joined my colleague, Senator Nancy Kassebaum. But, sir, I have often said, though I was all by myself, I was never alone because I could join in a common cause with good men to advocate an important legislation. And I count you in that category. I wanted to come here today and say to you that on behalf of the women of the Senate and the women of America, thank you for your very strong advocacy on these issues that are affecting us.

Senator CHAFEE. Thank you very much, Senator. You are generous. And I appreciate it.

Senator MIKULSKI. And I believe that this Breast and Cervical Cancer Treatment Act will be a very important legacy issue for you, Senator Chafee.

Let us go back where we were in 1988. When I came to the Senate, women were not included in the protocols at the National Institutes of Health in terms of important research. Funding for breast cancer research, cervical cancer, gender-specific research was indeed quite sparse.

Well, then working together, we corrected that gap and established the Office of Women's Health at NIH. We insured that we were in the protocols and increased the funding.

At the same time, there was a tremendous outpouring of volunteer support to race for the cure. Well, while we raced for the cure, we needed to be sure that women could be included in the screening because though we knew that we might not now have the cure for cancer, we knew that there were two important elements. Early

detection and early treatment would be the two things that we really needed to advocate.

Well, we worked together even in this Finance Committee, thanks to you and Senators Roth and Moynihan and Bentsen, all of those that were there in 1990. We included screening and treatment for women who were on Medicare.

Then, we took a look at the issues where women did not have private health insurance. And we found that there were women out there working very hard every single day, but they did not have access to important screening opportunities for both mammograms and pap smears.

That is when I became the architect of the breast and cervical cancer screening legislation and had the immediate support of members of this committee and in the Senate. And we passed it.

Now, in 1990, we passed the screening legislation. People of good will and common sense could say, well, Senator Mikulski, why did you not include treatment at that time?

Well, if you recall, Senator, we were in great deficits. George Bush was President. We were trying to sort all that out. Remember, all the issues and turmoil over the budgets of 1990 and 1991. We simply did not have the money. And we knew we could not get through the treatment component.

So we made a down payment. We took the first step with the belief that it would not be the only step. Well, now the time has come to take the next step and to include the treatment issue in our agenda and in our authorization and in our appropriation.

That is simply what this legislation is, that you, Senator Moynihan, Senator Snowe, Senator Rockefeller, and all of us are advocating. I am so pleased about this because it is a bipartisan effort and it shows what we need to be able to do for that next step.

This screening has been an absolutely fantastic success. In the 10 years since we passed that bill, close to 800,000 women have been screened. 56,000 had normal mammograms, but 4,000 were diagnosed with breast cancer.

Of those 4,000, about 3,500 were under the age of 65, almost 75 percent, but they were ineligible for Medicare coverage. They had no private insurance or it certainly did not cover these high-tech services. So now the time has come to ensure that if we do the early detection, we must provide the funds for the early treatment.

The current system right now is an ad hoc patchwork for providers, volunteers, and local programming. But, Senator, I know your viewpoint. You would say you cannot fund the treatment for breast cancer by asking volunteers to run bake sales.

We need to make sure that the private sector and the nonprofit sectors are involved, that they need to be in addition to government, not in lieu of government.

So that is what this legislation is. As you said, it would establish occupational State Medicaid benefits for coverage of certain women who have been screened and diagnosed with breast and cervical cancer under Title 15.

They would have to satisfy income and resource eligibility requirements and not otherwise have health insurance. And it provides the State with this option. And we have a model under the

Tuberculosis Optional Benefit Program, making people who had TB also eligible for this. So we have the legislative model.

As you know, today, sir, we are debating what to do with our surplus. Well, I think we ought to put our money into ensuring that we save lives. And I think that is a very modest program, but it is a very worthwhile program.

And I just wanted to comment and lend my voice in saying that now that we have taken the first step, let us take the next step. And I want to thank you for very important authorship of this bill. I am proud to be a co-sponsor. And I will do all I can to move this bill on a bipartisan basis. And again, thank you for your leadership.

Senator CHAFEE. Well, thank you very much, Senator. As I say, you have been for a long, long time, deeply involved in these issues and have given wonderful leadership in the whole area of women's health overall, but particularly I think of you in connection with these breast cancer problems.

And I think the point you make about this is optional by the States, this is not making the States do anything. If they do not want to do it, they do not have to do it. All we are saying is that if they do it, the Federal Government will pay its Medicaid half for the percentages in that.

I would wonder if you could say a couple of words about the effectiveness of the treatment. We all read in the last several days about Lance Armstrong and what he did in that great, incredible victory he achieved in the Tour de France having come back from cancer. And what can we say to these women if we can have this legislation? What are their chances?

Senator MIKULSKI. Well, I will tell you. When I saw Lance Armstrong on TV over the weekend talking about his victory and realizing that in 1997 he needed help to walk down the floor of the hospital after he had had chemotherapy and to see someone who could do a bicycle race of over 2,000 miles over 2 mountain ranges, I mean that showed three things: courage, the grace of God, and the genius of the American medical system and how far we have come in treating cancer.

We might not have the cure of all cures, but what we do have is that if we do the early detection and we can spot these tumors at a very early age, there are a variety of modalities, chemical, radiological, and even surgical to do the treatment.

The earlier the detection, the smaller the tumor, the less invasive the treatment and less debilitating, then usually you get in early and you get it out. This is what all the mortality and morbidity and wonderful data that the Center for Disease Control has on this points out, that the earlier the treatment, the more likely you can get the cancer out and the survivability rate is really significant.

Senator CHAFEE. It seems to me that what is the point of having the CDC give a detection to a woman if the woman cannot get the treatment? The whole thing, it makes no sense, except the only result is just to bring terror into the life of the woman.

Senator MIKULSKI. Well, first of all, for the 700,000 that were screened, and in my own State it was closer to about 58,000, many of the women do get treatment, but they get treatment based on

whether a State has voluntarily provided funds, the role of nonprofit organizations in raising money, and also the charity of physicians who often have provided their services for free.

However, under the shackles of managed care, there are less and less doctors able to do that. And there is a very important study that the Journal of the American Medical Association has provided us on that. So doctors have less opportunity to do philanthropic work. And also, you cannot fund this on a bake sale.

It is better to provide the screening. But right now, we have the treatment, but we have to forage for it. It is often late in coming. And it is also at the bare bones minimum.

Senator CHAFEE. Well, thank you very much, Senator. As I say, you have been a long-time battler in this arena. And we pay tribute to you and thank you for all you have done. And you have pledged to keep up your work. And we are going to need it because you are a very valuable ally in this.

Senator MIKULSKI. Sir, we are going to miss you. I do believe that this will be one of your really finest contributions. You have served the Nation in many capacities and for which we are grateful. You have served this committee in many capacities. But I think when we pass this bill, it is going to be one of your finest contributions.

Senator CHAFEE. Well, thank you very much. You are generous. And I appreciate it. Thank you, Senator.

And now, if the next panel would come forward. Mrs. Almond, the first lady of the State of Rhode Island. I am very proud that you are here, Mrs. Almond.

Barbara Matula, the Director of the Health Care Programs in the North Carolina Medical Society; Marlene McCarthy, Executive Committee, Board of Directors, National Breast Cancer Coalition; Carolyn Tapp, President of the Women of Color Breast Cancer Survivors Support Project; and Barbara Flett from the Women's Health Partnership of Suffolk County, New York.

Please take a seat anywhere, ladies. That is fine. The only tricky part is to make sure the mikes are on. And Mark will give you a hand in that.

I want to welcome Mrs. Almond, wife of our Governor at home. And I was so pleased that you are here. And I know that you have been very active in Rhode Island on this. So please proceed, Mrs. Almond. We are delighted to have you here.

STATEMENT OF MARILYN ALMOND, FIRST LADY, STATE OF RHODE ISLAND, PROVIDENCE, RI

Mrs. ALMOND. Thank you, Senator Chafee, for giving me the opportunity to testify. 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 for breast cancer. My husband and I have worked with the Rhode Island Breast Cancer Coalition to assist them in their ongoing mission to eradicate the disease.

Through our concerted efforts, our State employees raised over $17,000 in one day for research through the First Annual Lee National Denim Day last year. Proceeds from this event were distrib-

uted 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. And that is 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 would feel. We do not want one woman to experience that. We do not 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 4,000 economically disadvantaged women have received mammograms and 4,700 women have had pap tests.

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 need a long-term solution to this problem. That is 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 is 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 is why we must ensure that women who are diagnosed with breast or cervical cancer receive the proper medical care.

Whether it is enacting legislation requiring medical insurers to cover hospital stays for up to 48 hours for women undergoing mastectomies or whether it is 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 on 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.

Senator CHAFEE. Well, thank you very much, Mrs. Almond. And I appreciate your kind words here. And certainly, we are proud of the record we have been able to achieve.

And I think the points you made about managed care, that is a question I will be asking the others if they had similar experiences, but I suspect they have with so many doctors going into that. As you pointed out in your testimony, we have seen a dramatic decline in the number of medical professionals available to provide free medical care.

So thank you very much and we appreciate your making the effort to come down here.

[The prepared statement of Mrs. Almond appears in the appendix.]

Mrs. ALMOND. Thank you.

Senator CHAFEE. Next, Barbara Matula, Director, Health Care Programs, North Carolina Medical Society; Former Chairperson, National Association of State Medicaid Directors. Ms. Matula?

STATEMENT OF BARBARA MATULA, DIRECTOR, HEALTH CARE PROGRAMS, NORTH CAROLINA MEDICAL SOCIETY FOUNDATION, FORMER CHAIRPERSON, NATIONAL ASSOCIATION OF STATE MEDICAID DIRECTORS, RALEIGH, NC

Ms. MATULA. Thank you, Senator Chafee, for caring about women who are suffering with breast and cervical cancer, but I also want to thank you for helping all the vulnerable children and adults that you have in many decades in working with Medicaid.

Senator CHAFEE. You are nice. Thank you.

Ms. MATULA. In preparation for this testimony, I spoke with the head of the North Carolina Cancer Control Program in our Public Health Agency. I spoke with the secretary for the Department of Health and Human Services in North Carolina who oversees all of the programs Medicaid and public health purchases for care.

I spent a long time with the head of the eligibility section in Medicaid because as well as I know it, I can never believe the rules for disability and eligibility for Medicaid.

I spoke also to the past president of the Medical Society, an oncologist who practices in a teaching hospital and who had such vivid and chilling stories to tell me about patients with breast cancer who are uninsured that I even hesitate to repeat them for fear of dreaming about them again.

I spoke also to the soon-to-be president of the Medical Society who is an internist who had a lot to contribute about how we force people into a category of disability of permanence and of reliance of public assistance that really has shaped a lot of the testimony that I am going to give you now.

In the 20 years of working with Medicaid, I was one of the few Medicaid directors who had under her control eligibility policy.

Many of them did not. It is done in another agency. And there was a cartoon I think in the Washington Post that said it could be easier to explain the meaning of life than to explain Medicaid eligibility rules.

But because I had to do it in person to many unhappy people who could not qualify and who could not understand why they did not qualify, I would like to run through that quickly today because it is simply not a question of income alone that keeps these women from qualifying.

The general public believes that if you are poor, poor enough even if it is at Alabama's level and sick enough that Medicaid will help. Unfortunately, this is not true, not for adults between the ages of 18 to 65.

If you are poor and pregnant, Medicaid will help. If you are poor and raising a family, if you have minor children at home, Medicaid may help. If you are a child in a low-income family, Medicaid and now the Children's Health Insurance can help.

If you are over 65 and you cannot afford even your Medicare premiums, Medicaid will help. If you are in a nursing home and you have exhausted all of your private wealth and resources, Medicaid will help. And if you are seriously disabled either physically or mentally with a long-term and unable to work, Medicaid and eventually in 2 years, Medicare will help.

But if you are a single adult or a childless couple or if your children are already grown and no longer are dependents and you become critically ill regardless of how poor you are, regardless of how desperately you need care, not in any State of this union will we cover you under Federal Medicaid law until your illness has reached the stage when you are ready to die or determined permanently incapacitated.

That says that the condition must last for at least 12 consecutive months. If you can be cured in 11 months, you cannot get help from Medicaid. But if it will last 12 consecutive months and you are unable to work, you can probably draw SSI payments. The doctor will declare you permanently, totally disabled, or about to die, and then we will help.

So if your disability is temporary or curable, you are on your own. And it does not matter how poor you are and how expensive the medical care will be, you will be on our own to find it.

Imagine now that you can home tonight and you learn that someone in your family has a potential diagnosis of breast or cervical cancer. Your only concern is getting the best care. You have a sense of relief that she has regular care, regular exams. So you are hoping that it was caught early. And all you look for is full recovery.

But if you are that same woman and your income is below 200 percent of poverty which is so very little—if you are a single person that is $16,480 a year, if you are married it is $22,000 for the couple. That is very low, but it is twice what Medicaid eligibility is. You have run out of funds and you are left to your own devices.

In North Carolina, we have put $1 million in a cancer fund for 200 percent of poverty for these screened women by CDC. And the horror is we ran out of money early in the year. So they lowered the income test to 115 percent. And when they still ran out of

money, they told women whose diagnosis might not include a 5-year recovery that they could not help them at all.

This is unconscionable. For all the little administrative wrinkles in Medicaid eligibility, I hope this bill will pass.

Senator CHAFEE. Well, thank you very much, Ms. Matula, for supplying that testimony.

Ms. Marlene McCarthy, Executive Committee, Board of Directors, the National Breast Cancer Coalition here in Washington. Ms. McCarthy?

[The prepared statement of Ms. Matula appears in the appendix.]

STATEMENT OF MARLENE MCCARTHY, EXECUTIVE COMMITTEE, BOARD OF DIRECTORS, THE NATIONAL BREAST CANCER COALITION, WASHINGTON, DC

Ms. MCCARTHY. Thank you, Mr. Chairman and members of the committee, for inviting me to testify today and a very specific thank you to you, Senator Chafee, for understanding the complexity of this need and for sponsoring this legislation.

I am Marlene McCarthy, member of the board of directors of the National Breast Cancer Coalition, serving on the executive committee. I have breast cancer. And I am one of 2.6 million women in the United States today with this disease.

The National Breast Cancer Coalition is a grassroots advocacy organization comprised of over 500 organizations and 60,000 individual members dedicated to eradicating breast cancer through thoughtful activism, influencing public policy in cancer research, clinical trials, and access to quality health care for all women.

The National Breast Cancer Coalition has made the passage of S. 662, the Breast and Cervical Cancer Treatment Act a top priority. This legislation would establish a Federal treatment component for the CDC screening program which has screened more than a half million women for breast cancer. However, it does not provide any Federal resources to pay for treatment when breast cancer is detected.

Being a national organization, we are constantly informed of the personal difficult experiences women are having throughout the country securing treatment. From community bake sales to exhausting the child's college savings account to losing their homes.

Our members have witnessed the emotional and physical trauma of women whose treatments were delayed while they scrambled to find providers willing to give them free care. And instead of focusing on getting well, too many women have had to worry about getting treatment for their cancer.

The testimony of Mary Ann Waygan, a CDC program coordinator from Cape Cod, Massachusetts is included in my written testimony and illustrates the problem.

I would like to call your attention, Mr. Chairman, to the study released by the CDC in January, 1998 which demonstrates that although treatment was initiated for most of the women diagnosed with cancer, the system of treatment is tenuous and fragile at best.

Mr. Chairman, I have introduced the report from the CDC which summarizes the results of the study into the record. The CDC Early Detection Program needs a system that provides sufficient

funding for treating women. And their own report underscores this need.

The CDC study demonstrates the time and effort diverted from screening and education and directed to trying to network free care.

Today, the committee-wide initiatives to provide treatment is a voluntary and ad hoc system which cannot be relied on in the existing health care maze. It is not my intention to imply that the government-funded screening program is flawed.

Please, hear me when I say the screening component is successful. However, a program of screening alone will not save women's lives which I am sure is what Congress meant to do.

The issue is not just women not receiving treatment, but the women's struggle once diagnosed, wondering how and whether and when they will find treatment for their cancer and how they will handle a lifetime of bills to pay for it. We are also hearing that the numbers of medical specialists providing free or reduced fee care are dwindling as more are moving to a managed care practice model.

Mr. Chairman, I point you to a letter from Dr. Robert Brooks, a secretary of the Florida Department of Health and Human Services. This letter documents the strain medical providers are experiencing trying to provide uncompensated care to the women diagnosed.

The experiences demonstrated by Brooks are typical of those that we are hearing about from throughout the United States. If physicians providing care abandon the initiatives, then any attempts to expand the screening program can very seriously compromised.

Mr. Chairman and members of the committee, we are very grateful to you for your commitment to women's lives. This bill has exemplary bipartisan support.

Clearly, you recognize that a Federal cancer screening program can only be effective and save lives if it is coupled with treatment. States which may already experience fiscal strains will have an enhanced funding match through this optional Medicaid program.

Congress wanted to save lives of under-insured and uninsured women. So they enacted a Federal screening program. S. 662 provides the opportunity to complete this thoughtful initiative by providing the pathway for States to enact a guaranteed program of treatment.

The National Breast Cancer coalition is asking the committee to ensure that happens 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. And we look forward to working with you on this critically important issue.

Senator CHAFEE. Well, thank you very much, Ms. McCarthy. We appreciate your testimony. And we will have some questions at the conclusion of everyone's testimony.

I am delighted that we have been joined by one of our most distinguished members here and a gentleman who has been long interested in these types of problems and has been a leader in our efforts.

And, Senator, if you would like to proceed. Senator Bryan from Nevada has a wonderful record in doing the best he can in connection with women's breast and cervical cancer and other death challenges. Senator, we are glad you are here.

[The prepared statement of Ms. McCarthy appears in the appendix.]

OPENING STATEMENT OF HON. RICHARD H. BRYAN, A U.S. SENATOR FROM NEVADA

Senator BRYAN. Thank you very much, Mr. Chairman. I shall be brief because we want to hear more from our witnesses and give you an opportunity to explore any questions.

I want to acknowledge first your very gracious comments and secondly say to you, Mr. Chairman, that this committee in this Senate is going to miss Senator John Chafee. He is truly a statesman. And generally, they do not make those kind of statements until you are already out of the institution. The day after you leave, you are no longer a partisan advocate. You are an advocate. You rise phoenix-like from the ashes of the political warfare, but John Chafee has achieved that status in my judgment many times over.

I am pleased to be here. Mr. Chairman, I indicated to you yesterday when I saw you that because I know of your own leadership that I wanted to be here at least to express my strong support for this legislation. The optional provisions that are contained in that, gives the States the kind flexibility that they need.

And I just want to voice my strong support and to say to our distinguishes witnesses, I think probably the most terrifying word that any woman could hear is cancer. It has affected my own family. My father died of prostate cancer. And it really is a traumatic experience.

And I think those of us, my generation who were at earlier time less aware and less sensitive to the concern, have certainly become aware of this problem and the increasing statistical frequency. I must say my son is a physician, not in this particular area.

I do not understand why that is occurring. And some of you may have your own thoughts on that. Medical science may provide some insights, but it is just a terrifying prospect. So I am very pleased to be supportive of the legislation.

I commend you, Mr. Chairman, not only for your leadership for assembling the very distinguished panel of witnesses to share with us their thoughts. And I am pleased to be here in spirit as well as actual support of the legislation. And I thank the Chairman.

Senator CHAFEE. Well, thank you very much, Senator.

And now, we are going to hear from Carolyn Tapp who is President, Women of Color Breast Cancer Survivors Support Project of Los Angeles, California. Ms. Tapp, please proceed.

STATEMENT OF CAROLYN TAPP, PRESIDENT, WOMEN OF COLOR BREAST CANCER SURVIVORS SUPPORT PROJECT, LOS ANGELES, CA

Ms. TAPP. I appreciate the opportunity of speaking for the under served, uninsured women of Los Angeles. My name is Carolyn Tapp. And I am President of the Women of Color Breast Cancer

Survivors Support Project in Los Angeles. We have a membership of over 120 women. And these women are low income. Most of them have no insurance. And they have problems getting treatment for breast cancer.

Los Angeles had a $12-million grant at one time, but it has been exhausted. So now, the women have no place to turn when they are diagnosed with breast cancer, other than receiving some inadequate care. It is just that the treatment is so inadequate with most of the woman, it is just unbelievable.

Some of the women have mastectomies. They cannot afford prostheses. And they are wearing balloons with water in them to fill their blouses and make it look like they have another breast.

Some of them are sharing medications with someone else because they cannot afford to purchase medication. I myself have shared medications with some of the women who could not afford to purchase medicines in the State.

We had women last year that passed away with breast cancer. And most of them were screened through the screening program. And they had to scramble to find treatment. I heard that it takes 8 days to receive treatment, but in their cases it took 3 months to 6 months to receive treatment. One of the women passed away the day after she was approved for treatment.

And this is just unacceptable to me. I think that all women in this country should be afforded adequate medical care. And I urge you right now to make sure that all women get adequate care.

Some of the things you see in my community, you would not believe because these women are dying. Just last week I was here. When I returned, another women had passed away. And they are passing away so fast. Just this year, this is the fifth woman who has passed in my group alone. And some of it is so unnecessary.

And it is just a waste of time to go out and teach early detection because when you get them to go out and get mammograms and find out they have breast cancer, then it takes 3 to 6 months to get treatment. This is just unheard of. And I urge you right now to help the women in the under served community receive treatment. Thank you.

Senator CHAFEE. Well, thank you very much. I think your point about it is a waste of time to have the detection if there is not going to be any treatment is such a valid one.

Barbara Flett, Women's Health Partnership of Suffolk County, New York. Ms. Flett?

[The prepared statement of Ms. Tapp appears in the appendix.]

STATEMENT OF BARBARA FLETT, DIRECTOR, WOMEN'S HEALTH PARTNERSHIP OF SUFFOLK COUNTY, NY

Ms. FLETT. Thank you, Mr. Chairman and members of the committee, for inviting me to testify today. I am Barbara Flett. I am a registered nurse and 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 every State in the country.

As you said earlier, 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 underinsured and insured 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 service is incredibly labor intensive. 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. 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 to 15 percent of the eligible women nationwide. I believe that if there were a treatment component we would be able to screen more eligible women.

Last year, our program screened 2,200 women, 10 percent of whom require follow-up care. Judy Lewis was one of the women. I would 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. Judy's job did not provide health insurance. So when she felt the 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's diagnostic work-up came back showing breast cancer. It was not easy finding a doctor who would be willing to initiate her treatment.

However, when he did his lumpectomy, it confirmed our breast cancer diagnosis. As you can imagine, Judy was devastated. In the next 5 weeks, she required a wider margin biopsy and a partial mastectomy. Following three surgeries, she needed 7 weeks of radiation.

In order to get Judy treatment, we were able to convince one doctor to provide his service at one-third the regular cost. Unfortunately, we were unable to make similar arrangements with other physicians or the hospital. As a result, Judy now owes the bill for her radiation, anesthesiology, and other hospital charges. And she is in debt for more than $20,000.

I tell you Judy's story not so that you will feel sorry for her, but 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 the 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 it is hard work, there is no guarantee that we will be able to find treatment for these women.

Dr. Stanley Klausner, a board certified general surgeon specializing in treatment of diseases of the breast and director of breast services in Brookhaven Memorial Hospital in Patchogue, NY, understands the situation 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. His testimony is attached to mine.

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 with no insurance are often afraid to elect breast conserving surgery. They are so terrified of medical bills that their medical judgment is biased.

Despite their awareness that breast cancer may be amendable to breast conserving surgery, these women are electing mastectomies instead because they know the costs of additional treatment 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. Judy Lewis 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 women is diagnosed with breast or cervical cancer, they should not have to worry about when or whether they will be able to find treatment. 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.

Senator CHAFEE. Thank you very much, Ms. Flett.

[The prepared statement of Ms. Flett appears in the appendix.]

Senator CHAFEE. And Senator Bryan, if you have a question or statement here, this is a good chance.

Senator BRYAN. Thank you very much, Mr. Chairman. These are pretty heavy days to be the acting chairman here.

Let me ask a question to anyone of the panel. Do we have any indication as to how many States will elect to participate in this program if this legislation is passed as I hope it will be? Is there any data that is available to us, any information that you might have?

Ms. McCarthy, you look poised, ready to respond.

Ms. MCCARTHY. I am kind of ready to respond. I cannot tell you what States have made any type of indication that they would in fact embrace an enhanced match. I can tell you clearly, and perhaps you missed Mrs. Almond's very eloquent remarks——

Senator BRYAN. And I apologize to the first lady.

Ms. MCCARTHY [continuing]. Where she said that Rhode Island was very willing to step out and present a leadership role.

I can speak from the intention of the National Breast Cancer Coalition which is a phenomenal grassroots organization. And we are ready on the dime to mobilize our national network to encourage States, in fact, to embrace this enhanced match.

We all in the field understand how serious this is. We are working with it as volunteers day after day. We know that this legislation, a screening legislation, is unconscionable without a treatment component. And I think we all agree at this table and in this room.

So clearly, we are going to make this happen. And we are the women with breast cancer who can make it happen.

Senator BRYAN. Let me say it is not only unconscionable, it is kind of a cruel hoax to invite somebody in for a screening, relay the tragic news and then tell them there is no treatment readily available.

Ms. MCCARTHY. Right.

Senator BRYAN. That is almost inviting somebody in on false pretenses. And we need to change that. If you are going to do the screening and the diagnosis and it is not as you would hope that there is a positive indication of cancer, I think the reasonable expectation is that there would be treatment available.

In this country, we do not generally say we will give screening, but if the news is bad, then you are going to have to go somewhere else and we do not know and we do not have a program for it. So I think your point is well taken.

Again, the point that I made, in the brief comments that I made, that I do think all of you collectively in this movement in the country do a very, very good job of impressing upon the American people and legislators and public policymakers, generally, just how devastating this is.

I would not presume to suggest that I have the understanding of those of you who work in the field, but I will tell you, a few years ago I went to the White House. We were working on a drive-through mastectomy bill. Some of you may recall that.

And a young woman who I did not know who is a staffer in the House of Representatives came in and described her situation. I thought I was reasonably knowledgeable, no expert on the subject.

I mean, it was a very, very powerful recitation of what literally tens of thousands of women go through. And it was such that I do not think anybody in that room would have failed to respond by urging his or her Governor to say, look, we need to take action. So I think that your expectation is correct.

Help us out a little bit. I see that our chairman is back. And so I will abbreviate my questions and comments, but we do occasionally in the Senate as we say in Nevada, catch lightning in the jug.

We really do once in awhile, maybe it is the alignment of the stars, do the right thing. Or we think that we are doing the right thing only to be terribly dashed in terms of our hopes and expectations that people will take advantage of this.

I know, for example, and Senator Chafee was a strong leader in this committee on the floor, we did something to expand the options available for health care for children who kind of fell in that spectrum where they did not qualify for Medicaid, but clearly their families did not have the ability to purchase health insurance. And I must say that the results have been, notwithstanding the best of our indications, tragically disappointing. There is money available. There are programs there, but our outreach efforts have failed.

Help us get an understanding as to how these outreach efforts could be made more effective. And I realize that we are not talking now about children's health care.

I suspect there is some parallel with some of these individuals who are diagnosed who would be eligible for treatment if the States embrace this enhanced Medicaid match. It may not be forthcoming. That is hard for a lot of us to understand that, but I think that is a reality that we might face.

If you anticipate that problem, would you share with us what your strategy is to have a more effective outreach program? And I think Ms. Matula is ready to enlighten me.

Ms. MATULA. I have a finger on each one of those topics. First, looking at it as a State budget officer would look at it, I cannot tell you how many States have State-only funded programs or local-only funded programs, but I can guarantee you that those that do, do not have enough funds to meet all the needs, similar to what I described in North Carolina.

They would take those State and local funds now and use that match. And almost immediately, it would serve two or three times as many people. It is as much an issue of reaching out as much as it is today we are turning them away when we have the lower-income test from 200 percent to 110 or 115.

Every program needs a chance to get started up. And the Children's Health Insurance Program really started with fits and starts in many legislatures. They did not know quite what to do. And they need more time.

But the Children's Health Insurance Program like so many of our Medicaid outreach efforts are usually triggered by a need. It is when a child shows up in the emergency room uninsured that you have a social worker ready there to take an application, tell the parent what is available to them and that they do not have to use this source of treatment as their primary care treatment from now on.

I think in this issue with the early diagnosis and screening programs that are out there, you will just have to pray that you do not have to turn them away. I do not think outreach will be an issue because the medical condition will trigger the need.

And I know that medical societies across this country would be more than willing to get the word as quickly as they can to their participating doctors and doctors to hospitals.

Senator BRYAN. That is your hope and ours as well.

Did anybody else want to respond to that before I yield back to our chairman?

Ms. MCCARTHY. I would just like to say that clearly it was the intention of Congress to save women's lives. I alluded to that in my oral remarks.

But this is a recovery that we do have to do. We have to complete the program. We are going out and putting all of our efforts in the community to break down barriers for women to come in for screening. We are dealing with a variety of issues from ethnicity to religious to gain the confidence of the women in special populations to come in for screening.

We are spending a tremendous amount of time in educating them so that they will come and then telling them that Congress wants you to be screened. This is a program your government is putting forth to save your life. Well, the piece that is missing is what can certainly come back to haunt us. We are hearing it already. And we cannot let that continue.

Senator BRYAN. Well, I quite agree. I would just say that in some parts of the country, this is a program that your Congress wants you to take advantage of would be perhaps counter productive. At least in some parts of the country, that would not enhance the credibility of the program per se.

Ms. MCCARTHY. It would be twisted.

Senator BRYAN. We have lightning in the jug on this.

Ms. MCCARTHY. Right.

Senator BRYAN. This is certainly something we must do and certainly something that we are going to do I am sure under Senator Chafee's leadership.

Ms. Flett, you look like you were about ready to offer a comment?

Ms. FLETT. No, I have nothing.

Senator BRYAN. Mr. Chairman, I thank you again for your courtesy.

Senator CHAFEE. Thank you, Senator Bryan.

Ms. Flett, I would like to ask you a question. You are one of the people, your organization does the screening.

Ms. FLETT. I am the director of that program.

Senator CHAFEE. I am not sure how that works. In other words, they say that the CDC, Center for Disease Control, out of Atlanta is the one who is in charge overall of the screening program. How do they affect you? Do they provide the funding for you to do your screening?

Ms. FLETT. They provide the funding as I understand it to the New York State Department of Health who coordinates the program in 53 counties. So there is 53 partnerships out there. Suffolk County is one of those partnerships. So then, they send the funding down to the local partnership.

Senator CHAFEE. So in a way your funding comes from that source?

Ms. FLETT. Yes.

Senator CHAFEE. Your salary and so forth?

Ms. FLETT. Yes.

Senator CHAFEE. And then, you say that currently, you are only to able screen 12 to 15 percent of the eligible women nationwide. Is that true in Suffolk County, too?

Ms. FLETT. Yes. The statistics are similar to what we have heard. New York State has their own data. And in our regional meetings, that is about right. And actually, 10 percent was what I heard up in Albany.

Senator CHAFEE. Earlier, you heard us discuss Lance Armstrong and him coming back from the cancer that he had. And as I read the accounts, it seemed to me his treatment was chemotherapy primarily.

And this is a question that is asked, and if anybody on the panel could answer it could help me. You talked of the difficulty of getting doctors now because so many of them are on managed care, but sometimes you can get them. And indeed, I think you noted some that had helped you out.

But that is the doctor offering up his time, his services which many do. But what about the chemotherapy, the machines, and equipment and operation of the chemotherapy equipment? I am not even sure exactly what it looks like, but I presume it is one of these mammoth machines that looks like an x-ray machine. Am I correct in that?

Ms. FLETT. No. Chemotherapy can be delivered in a number of ways. But I think it is important to point out, in Suffolk County when we can find a provider to offer pro bono services, an oncologist to deliver a chemotherapy regime to a woman, he is willing to participate and offer his time.

We then have to find the drug. And so it is only the physician that can make application to the indigent drug programs that exist. So not only has he agreed to offer his time, now he has offered his office staff time in filling out applications that are lengthy. And they must get drugs.

One of the problems we had in our program was that one of our oncologists did not want to delay treatment. Yet, the indigent drug program that was sending antiemetic or antinausea drugs that usually accompany chemotherapy for women could not get it there in time.

So I spent the better part of a whole day, calling hospital pharmacists to see if we could get it on loan until it arrived in the mail when we can reimburse the pharmacy for the loan. So it is more than just getting a provider to provide pro bono services. There is a lot more involved.

Senator CHAFEE. I can see that. And so it gets more complicated than just getting the doctor to offer his services.

Ms. FLETT. Right.

Senator CHAFEE. Ms. Matula and the others could also answer this, if you would. Some have suggested that CDC provide the treatment as well as the screening, in other words forego Medicaid. What would you say to that?

Ms. MATULA. If it was the last resort, I would say do it, of course.

Senator CHAFEE. Do not put it in the last resort category. Move it up. Let us say you were queen.

Ms. MATULA. Oh, good, I like that. [Laughter.]

Senator CHAFEE. Would you have CDC treatment programs?

Ms. MATULA. The only reason I would not do it is that, and this was after talking to a fellow with many years experience with the CDC programs, they have no experience as third-party administrators. Their job is to do public education and outreach which they do very, very well.

To duplicate what an existing program already is in the business of doing——

Senator CHAFEE. Meaning Medicaid?

Ms. MATULA. Meaning Medicaid. Learning how to reimburse physicians and hospitals and pharmacies and clinics and doing it in a quick turnaround time so that they will continue to participate would be a waste of our time and resources to duplicate this is in another agency.

Senator CHAFEE. Suppose this legislation passed. And what it does is provide Medicaid coverage for this group of individuals. And as you know how it works, it is basically a 50/50 split. And what all this means is if the State wants the Federal Government will come in and match it 50/50 for Medicaid.

Ms. MATULA. That varies among States.

Senator CHAFEE. Yes, I know, but let us say roughly 50/50.

Ms. MATULA. 50/50.

Senator CHAFEE. And now, do you think that will work out pretty well? Let me try Ms. McCarthy. Do you think that will work?

Ms. MCCARTHY. Yes, I do. I clearly do. I think the States are already feeling fiscal strain in trying to help these networks of care.

And I truly believe from the advocates that I have spoken with, the breast cancer advocates across the country who are now currently volunteering in this program trying to get networks for care for the women diagnosed, that clearly this will work.

Most of us are speaking with the officials at our State houses.

Senator CHAFEE. I have been corrected here which is not unusual. And our bill has a 75 Federal match.

Ms. MCCARTHY. 75/25.

Senator CHAFEE. And only 25 States. So that really is tempting. I do not think under the regular Medicaid formula any State has reached—maybe Mississippi, but I do not know.

Ms. MATULA. That means that $1 million North Carolina spends today would buy $4 million worth of care.

Senator CHAFEE. Well, that would be terrific. So in other words, does the whole panel agree that if we are going to do this, do it with Medicaid? What would you say to that, Ms. Tapp?

Ms. TAPP. I would say do it through Medicaid, but with some improvements.

Senator CHAFEE. All right. Would Medicaid have problems interfacing with another program's eligibility standards? Would Medicaid be able to easily enroll and cover those that are found eligible in screening done under the CDC program? In other words, now we have the CDC.

Well, I have sort of asked this question before, but how do you think Medicaid will work out with all of this? Do you think it is the best of the possibilities?

Ms. MATULA. If you would have asked me this 15 years ago, I would say we do not even speak to our public health agencies, but

in that interim, we have learned how to do it with the pregnant women coverage to reduce infant mortality where the determination of pregnancy serves as presumptive eligibility, where the income tests at that time were easily twice as high as we had for the women on welfare who were the only other women.

I do not think this would be a problem. The State Medicaid agency and the public health agency could have a cooperative agreement that would spell out those 200 percent of eligibility and that screening as the trigger. And it could be smooth as silk.

Senator CHAFEE. What do you say to that, Ms. Flett?

Ms. FLETT. As a program director, quite honestly I would recommend—I would welcome anything that provided treatment services to the women that we screen through our program.

And I am probably not the best prepared to speak on whether Medicaid is the best program, but it seems to work. A lot of the women, we work hard when they are diagnosed to get on Medicaid. So it seems like the appropriate program.

Senator CHAFEE. All right. The CDC points out that many women have started through the screening program, but once you get them started, do you stick with them and follow up? And what about reconstructive surgery? Can you give them any help on that?

Ms. FLETT. Sure. The programs are kind of stressed and the staffing is limited. We have recently added to our partnership a patient navigator which has been helpful in getting the woman some of the services and linking services. But when services do not exist, you cannot link.

Reconstructive surgery is one of those services where no plastic surgeons are jumping to offer reconstructive surgery to the women we screen. And it is very hard to be on the other end of the phone telling a woman, no, I cannot find that service for you. We are happy when we can get the mastectomy or the lumpectomy at a reduced or pro bono way for the women. Reconstructive surgery is really not an option.

Senator CHAFEE. Senator, do you have any further questions?

Senator BRYAN. I do not really.

Senator CHAFEE. You might say to us if this all makes such sense, what is going on around this place? Why does it take you people so long to get something done? This is optional. We are not demanding that any State do it. We are just making it available.

And the answer to that is, well, I have trouble finding the answer sometimes, I will confess. But the answer usually given is that, oh, well, we do not want to make special exceptions for specific diseases, if you would, that if we do it for breast cancer and cervical cancer, the next thing we will be extending Medicaid to all AIDS patients or whatever it might be.

But the answer to that reply it seems to me is, look, we are already in the business through CDC. We have already started part of this.

I think Senator Mikulski said, we took one step and now we should take the other step. And I think that is quite accurate that we took the one step, namely, the screening through a Federal Government agency. And now that we have done that, we ought to go the next step.

As Ms. Tapp was pointing out, we cannot go halfway and leave these women to die as she graphically pointed out.

But nonetheless, that is why this bill has not passed so far. We will keep plugging. As that old hymn says, we have the strength of 10 because our hearts are pure. All right.

Thanks so much for all of you. You are wonderful to come. And Mrs. Almond, Ms. Matula, Ms. McCarthy, Ms. Tapp, and Ms. Flett, thank you all very, very much. We appreciate your being here.

[Whereupon, at 3:40 p.m., the hearing was concluded.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

PREPARED STATEMENT OF MARILYN ALMOND

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.

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.

60-638 99 - 3

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

Statement of Senator Bob Graham
Senate Finance Committee
Subcommittee on Health

The Breast and Cervical Cancer Treatment Act of 1999 (S. 662)

July 27, 1999

Mr. Chairman, I would like to thank my good friend Senator Chafee for holding this important hearing today on the Breast and Cervical Cancer Treatment Act of 1999. I am a proud cosponsor of this legislation and look forward to the testimony is support of this bill.

Recognizing the value of screening and early detection, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990. This Act authorized the Centers for Disease Control (CDC) to provide critical breast and cervical cancer screening services to older women, women with low incomes, and women of racial and ethnic minorities. This legislation, which created the National Breast and Cervical Cancer Early Detection Program, provides services to women in all fifty states, the five U.S. Territories, and the District of Columbia.

Since its inception nine years ago, the National Breast and Cervical Cancer Early Detection Program has provided more than 950,000 mammograms and 1 million Pap tests to women. According to the CDC, almost half of these screenings were provided to minority women. While this program receives approximately $158 million, it is only able to screen about 12-15% of the eligible population.

As a founding member of the Congressional Prevention Coalition I feel strongly that preventive medicine must be taken seriously. This bill speaks to that point. In fact, mammography is the most effective method for early detection of breast cancer. Although deaths from cervical cancer have decreased approximately 70 percent in the past 40 years 14,500 new cases were expected in 1997. Virtually all cervical cancer deaths are preventable through early detection and appropriate follow-up.

Florida has taken the prevention of breast and cervical cancer seriously. The state has had a comprehensive prevention program for the early detection of breast and cervical cancer since 1994. It has implemented a statewide television and radio public education and outreach campaign, while targeting specific populations with lay health advisors, outreach workers, and

population-based flyers.

Although ensuring quality screening for early detection is an effective tool for controlling cancer, screening alone is not sufficient to prevent unnecessary illness and death. The legislation we passed in 1990 does not authorize the CDC to pay for treating breast and cervical cancer. This omission has placed undue burdens on states which are required to treat women afflicted with cancer under the terms of the grants they receive. Because they are overloaded, states have been forced to be creative in securing treatment services for women. A recent CDC study found that state efforts to obtain these treatment services were short-term, labor-intensive solutions that diverted resources away from screening activities.

The Breast and Cervical Cancer Treatment Act of 1999 (S. 662) would give states the option to provide Medicaid coverage for the duration of breast and cervical cancer treatments to eligible women screened through the CDC program. I believe that since states are required to provide these treatment services, giving them the option to access Medicaid funds shows our support for greater federal-state partnerships.

Underserved women who participate in this prevention program should not have to depend on fluctuating state and local government support and the generosity of medical providers. Instead, they deserve a guarantee that if they are diagnosed with breast and/or cervical cancer through this program, they will be able to receive cancer treatments that will prolong their lives. We should provide states with a vehicle to do just that. That is why I support this legislation.

Thank you, Mr. Chairman.

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.

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 3,600 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 cannot 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 <u>may</u> 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 1999 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.

Senator Mack
Page three
June 22, 1999

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

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-

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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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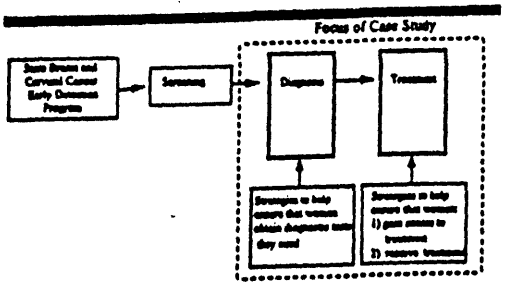
Goals of the Study

- 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?

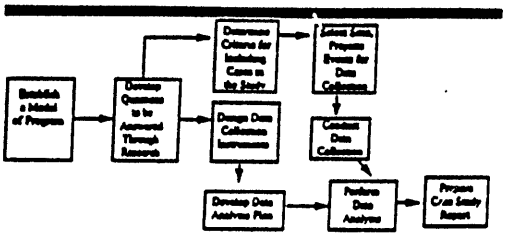
Phases of the Study

- 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	NV	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	3	7	23	9
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	193	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.

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.

Statement by Senator Olympia J. Snowe
Subcommittee on Health Care
Finance Committee
July 27, 1999

Chairman Chafee, I would like to applaud your leadership in convening this crucial hearing on an issue so vital to the health and lives of so many low-income women -- coverage of breast and cervical cancer treatment in the Medicaid program. And I am pleased to join on this panel, my colleague Senator Mikulski, someone with whom I have worked for many years on the issue of breast cancer in both the House and the Senate.

In 1990 I was a proud cosponsor of the legislation that established the Center for Disease Control's National Breast and Cervical Early Detection Program. We did this because we wanted to ensure that medically under-served women in this country receive regular screening for breast and cervical cancer. Since the program did its very first screening in 1991, over one million women have had either a mammogram or a test for cervical cancer, with more screened every

day. It is unquestionable that early detection is our best weapon against cancer, and this bill ensures that women who would not otherwise have access to treatment to further fight their cancer, *will* now have access to necessary treatment.

The success of the CDC program is proven. Today, 4,137 uninsured, low-income women across the country now know they have breast cancer. And 4,330 uninsured, low-income women across the country now know they have either invasive cervical cancer or pre-cancerous cervical lesions. In a battle where knowledge is key, these women now have a fighting chance.

Right in my home state of Maine, 4,301 women have gone through the screening program since it began in 1995. As a result, 28 women with breast cancer and 12 women with cervical cancer have vital information that they might not have had otherwise. I hesitate to think that they might otherwise be living with this disease growing undetected, if not for this groundbreaking program.

But as we well know, screening alone is not enough to save a woman's life. It is, in fact, only the first step. And the sad fact remains that despite all our scientific advances and despite new treatments and technologies, breast and cervical cancer will kill more than half a million women this decade alone.

When the National Breast and Cervical Cancer Early Detection Program passed in 1990, we wanted to ensure that women would receive not only screening but treatment as well. We wrote the law to require states to seek out services for the women they screen in order to receive timely and appropriate treatment. But the state programs are overwhelmed. Program administrators are scrambling to find treatment services- and even then these uninsured, low-income women must somehow come up with the money for costly procedures.

In Maine, for example, if a low-income woman is screened and follow up is necessary, the State refers her to nonprofit organizations such as the Maine Chapter of the National Breast Cancer Coalition and

the American Cancer Society. These groups help the woman try and find the funds to take the next step.

Mr. Chairman, there has got to be a better way. It is simply not right to provide women with the means to discover a killer disease, only to tell her she's on her own if she tests positive. That is why the bill before us today is so important. It provides states with the tools - through the Medicaid program - to provide treatment and complete the continuum of care.

Let me illustrate why this legislation is so important. One of my constituents went through the Maine Breast and Cervical Health Program and had an abnormal mammogram, followed by an abnormal ultrasound. She was advised to have a sterotactic biopsy but delayed for *three* months because she could not afford it. Three months for her cancer to grow and spread. And while she eventually had the biopsy and was not diagnosed with cancer, those three months as we all know could very well have meant the difference between life and death.

The women who enter this program have already been through enough being diagnosed with cancer. But to compound this stress, to leave a woman with the knowledge that she has cancer, that she must - absolutely must - receive treatment or die, but to not help her find the means to fight for her life is unconscionable.

We cannot sit back and claim that a screening program is enough save a woman's life. We cannot lead a woman to a diagnosis and then walk away from the result. We must provide an option for uninsured women who are not able to pay for treatment on their own.

This legislation strikes close to my heart as I know it does to members of this Subcommittee - more than half of whom have cosponsored the bill we are discussing today. And I believe strongly that we must pass it -- and that we must pass this legislation as soon as possible. I look forward to working with you to make that happen.

Thank you.

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.

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