BREAST AND CERVICAL CANCER FEDERALLY FUNDED SCREENING PROGRAMS

HEARING
BEFORE THE
SUBCOMMITTEE ON
HEALTH AND ENVIRONMENT
OF THE
COMMITTEE ON COMMERCE
HOUSE OF REPRESENTATIVES
ONE HUNDRED SIXTH CONGRESS
FIRST SESSION
ON
H.R. 1070

JULY 21, 1999

Serial No. 106-42

Printed for the use of the Committee on Commerce
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Mr. BILIRAKIS. The hearing will come to order.

The topic of today's legislative hearing is H.R. 1070, legislation introduced by our colleagues Rick Lazio and Anna Eshoo. This bill would allow States to expand coverage under the Medicaid program to certain breast and cervical cancer patients who were screened under the National Breast and Cervical Cancer Early Detection Program. I was pleased to join many of my colleagues on both sides of the aisle on cosponsoring this legislation.

Members of the subcommittee have a record of working together on a bipartisan basis to improve women's health, including efforts to fight breast and cervical cancer. Last year, the subcommittee approved a Mammography Quality Standards Reauthorization Act, which was enacted into law to ensure safe and accurate mammograms. The new law requires that women receive direct notice of their mammography results in writing.

In March, the subcommittee held a hearing to raise awareness of the threat of cervical cancer and the importance of regular Pap smear exams. Experts emphasize the need to better understand how cervical cancer is transmitted and the importance of early detection. They noted that cervical cancer is readily treatable, if caught at an early stage.

Today we will discuss how best to ensure that breast and cervical cancer patients receive the treatment that they need. In particular, we will focus on women screened under the National Breast and Cervical Cancer Early Detection Program, which is administered by the Centers for Disease Control and Prevention.

Last year, legislation, that I am proud to say I sponsored, was enacted into law to reauthorize this important program and other women's health initiatives at the CDC and the National Institutes
of Health. That bill, the Women's Health Research and Prevention Amendments of 1998, enjoyed the support of full committee Chairman Bliley, the Ranking Member Dingell, subcommittee Ranking Member Brown and many of our colleagues. An important provision of the bill, which was included at Representative Lazio's request, explicitly authorized case management services to assist breast and cervical cancer patients in obtaining treatment. Since 1990, the CDC's program has screened approximately one and a quarter million women in every State in the country for breast and cervical cancer. Mr. Brown and I had the opportunity to learn more about this important program from Dr. Nancy Lee, Director of the Division of Cancer Prevention and Control during our recent trip in the CDC's Atlanta headquarters, and I am very, very pleased to welcome Dr. Lee to our hearing this morning.

I also want to welcome all of our other witnesses, Fran Visco, President of the National Breast Cancer Coalition; Susan Braun, President and CEO of the Susan G. Komen Breast Cancer Foundation; Carolyn Tapp, President of the Women of Color Breast Cancer Survivors; and Dr. Stanley Klausner, a surgeon who volunteers his time to treat patients.

Before we begin, and before I recognize my very good friend Mr. Brown, I want to make one personal comment. I have noted, with regret, and I mean with great regret, an increase in partisan rhetoric during our subcommittee's recent deliberations. While I respect each member's views, I hope and expect that our discussion of issues of this magnitude will be conducted in a bipartisan atmosphere. No one should use breast and cervical cancer patients as pawns to score political points.

I look forward to the testimony of all of our witnesses, I hope they can help us understand the best course of action to help breast and cervical cancer patients obtain the treatment they need, and recognize Mr. Brown for an opening statement.

Mr. BROWN. I thank the chairman. I would like to yield my time to my friend from California, Ms. Capps, who has a markup, and I will let her go first if she would.

Ms. Capps.

Mrs. CAPPS. I thank——

Mr. BILIRAKIS. You are yielding your turn, not your time.

Mr. BROWN. And my turn and my time if you insist.

Mrs. CAPPS. I don't want to take my colleague's time.

Mr. BILIRAKIS. Ms. Capps, please.

Mrs. CAPPS. Thank you. I appreciate my colleague's relinquishing of his time, not his time but his turn, so I can attend another Commerce Committee markup.

Good morning to you all, and thank you to our chairman for holding this important hearing today on the Breast and Cancer Treatment Act. This bill now has 260 cosponsors with outstanding bipartisan support. Earlier this year, I was pleased to join Congresswoman Anna Eshoo and Congressman Rick Lazio in introducing H.R. 1070, and I have been proud to join them in gathering support for this important legislation.

I would especially like to welcome one of our expert panelists from my home State of California, Carolyn Tapp, President of the

This bipartisan bill gives States the option to provide Medicaid coverage to uninsured or underinsured women who have been diagnosed through the National Breast and Cervical Cancer Program called NBCCEDP. Approximately 3,600 low income women per year are screened through this program and often cannot afford treatment for desperately needed services.

These women are often slow in seeking out screening, sometimes with very sad consequences, but imagine being screened, having this terrible diagnosis, and then having no resources for treatment.

As a nurse, I am acutely aware that all of the screening in the world won’t help if women who are diagnosed do not have access to quality treatment for their condition. In addition, these women are often left to an ad hoc patchwork of providers, volunteers and charity care programs making their treatment unpredictable, delayed or incomplete.

A study released by the Centers for Disease Control in January 1998 found that although treatment had been initiated for most women in whom cancer was diagnosed, the system of treatment was tenuous and fragile at best.

And this is what we are talking about today. Not only is it worrisome that some women are not getting treatment but those who are getting treatment are not getting it—are getting it in a piece-meal fashion. Many women must seek charitable services from doctors for their treatment.

Some women experience time delays, and as we know, for cancer patients time is a most precious commodity. Every day, every minute counts. We cannot leave these women to basically fend for themselves as they are going through one of the most challenging and frightening experiences of their lives.

Cancer victims and their families cannot rely on a treatment system that cannot sustain itself. Long-term solutions are greatly needed, and that is what the Breast and Cervical Cancer Treatment Act provides. It allows States the option to provide Medicaid coverage to uninsured or underinsured women who have been diagnosed through NBCCEDP. To encourage participation, the bill also provides that States who take up this option would receive enhanced Federal matching funds.

Breast cancer experts from the Santa Barbara Breast Cancer Institute in my district have offered their strong support for this bill. In the words of Dr. Alison Mayer-Oakes, the Breast and Cervical Treatment Act will greatly improve underinsured and uninsured women’s access to more timely breast and cervical treatment. More timely treatment will be a matter of life and death. It will significantly improve the quality of life and survival of these women.

I would like to reiterate my thanks to the chairman for holding this hearing, but what we really need now is a markup to move this bill out of committee and onto the House floor. Our list of 260 cosponsors from both side of the aisle speaks loud and clear. The time has come to pass this significant legislation.

So, Mr. Chairman, I call on you to hold a markup on this bill right away, but seize this opportunity to ease the suffering of women with breast and cervical cancer around this country.
I yield back the balance of my time.

Mr. BILIRAKIS. Thank the gentlelady.

Mr. LAZIO. Thank you, Mr. Chairman. Let me begin by thanking you for holding this hearing and for your support. As Representative Capps has mentioned, we have over 260 cosponsors now on this legislation, 25 out of the 30 subcommittee members of this subcommittee are cosponsors, three-fourths of the full committee are cosponsors of this legislation. And I want to thank you personally, Mr. Chairman, for not just your cooperation and your interests and your commitment to this, but your commitment to this particular piece of legislation about becoming a cosponsor.

Everybody here knows that the screening program, the CDC screening program, is largely a success, but that screening is only half the battle. As the system currently stands, most women do receive treatment. No one is denying that, but based on the testimony that I have read and that we will hear today, there is some disagreement as to the quality of the treatment and the timing of the treatment that many women received.

After reading Nancy Lee's written testimony, one might believe that the program is operating almost perfectly, but I question whether CDC actually looked beneath the surface of their members. And CDC's own recent study of the program that Ms. Lee cites in her testimony, the conclusions are not so rosy.

The study I read found that developing and maintaining a network and a system for diagnosis, follow-up and treatment takes an enormous amount of time and effort. Treatment, the study says, is short-term, labor intensive and diverts critical resources away from the screening program. As a result, doctors and other providers are not inclined to participate, restricting the number of women screened.

Also the managed care environment limits the number of doctors willing and able to offer free or reduced fee services. Treatment is cited as one of the study's recommendations.

I am quite frankly also disappointed in the testimony of the Komen Foundation. At my request, several months ago my staff first reached out to them on several occasions to discuss the legislation, any concerns that they might have on this bill; unfortunately no concerns were forthcoming. I don't want people to misread what I am saying here. It is that I am not a supporter for Race for the Cure. I think it is a wonderful organization, I applaud the people that work there, I enjoy working with Priscilla and Senator Mack, but I want to register my disappointment about the lack of communication.

I know there is some opposition to this bill, people will cite numbers showing that the program helps women find satisfactory treatment, but I want to tell you that is not true in all cases. Judy Lewis from my district is not a number. She is a human being dying from cancer and she is not finding the cure she deserves as a woman screened by the Federal Government.

She was a waitress and didn't have the insurance through her employer like many people who work in low income and small businesses. I invited her today to speak to the committee about her experience in the screening program, but she couldn't be here, be-
cause after finding no option but to spend out all of her money, she had to attend her own Medicaid fair hearing to determine whether she is eligible for the program. She had to wait 1 year almost to the day for this Medicaid hearing.

Her story is a moving one and I guarantee you there are many, unfortunately many Judy Lewises, hundreds of them in each and every one of our districts.

So, Mr. Chairman, I thank you for scheduling the hearing and for all the work you have done for women in this program. I hope we can quickly move this bill through the legislative process. My commitment to women in this program will not end here.

I know that those of us who are working hard for this will also fight for Judy and many like her, and I want to thank Ms. Eshoo, who has been of invaluable help frankly in getting to that 263 member cosponsor. We had set a goal and it was Anna’s suggestion, let us set a goal of 218, half the House by Mother’s Day, and I think we started the date—the day before we broke with, what was it, Anna, something about 170, we got 40 or 50 that last day. So it was great work, we got over our goal for Mother’s Day. It would be a great Mother’s Day gift for us to be able to deliver this piece of legislation for women.

Thank you, Mr. Chairman.

Mr. BILIRAKIS. Thank you. It is not easy to say no to Anna Eshoo. I will verify that.

Mr. BROWN. Thank you, Mr. Chairman. I would like to thank you for arranging today’s hearings and congratulate Ms. Eshoo and Mr. Lazio for their hard and very effective work on behalf of this issue.


The program is federally funded and locally operated in the States. My home State of Ohio has 12 local screening sites providing coverage from all 88 counties. Since the Ohio program’s inception 16,000 women have been screened for breast and cervical cancer and cancer has been detected in more than 200 women. Early detection, as we all know, can alter the odds of successful treatment, dramatically restoring precious years otherwise lost to these devastating cancers.

But there is a catch. Early detection is a futile and ultimately cruel exercise if a cancer diagnosis does not trigger appropriate treatment. The two obviously go hand in hand. The 1990 bill authorized funding for screening but not for treatments. Instead it calls on States to secure treatment for women diagnosed with cancer under the screening program. But as it turns out, the onus responsibility has fallen on the local screening programs.

Staff at the screening sites typically do two jobs, arranging screenings and trying to convince doctors and hospitals to provide free cancer care to patients. This is a labor intensive hit or miss effort that places an immense burden on screening programs with no guarantee that women will receive timely care on a consistent basis. And the health care system shaped by the managed care in-
dustry providers inevitably more and more every year will have less flexibility to offer their services and their time for free.

The Federal Government invested $158 million in the breast and cervical cancer screening program in fiscal year 1999, yet we are only reaching up to about perhaps 15 percent of the target population. And when the women we have invested in are diagnosed with cancer, our commitment to them unfortunately has ended.

CDC cancer screening resources should be used to provide cancer screening. Health care resources should be used for health care, and that is where Medicaid comes in. The title of the original authorization is the Breast and Cervical Cancer Mortality Prevention Act, but mortality prevention requires screening and treatment.

H.R. 1070 would fill in that gap. It would establish a modest optional Medicaid enabling the Federal Government to contribute to the costs of providing proper care for these women.

By freeing up screening program resources and eliminating the uncertainty around treatment for women screened under the CDC program, H.R. 1070 would permit the Nation to achieve the full public health potential of the breast and cervical cancer screening program. We need to fight breast and cervical cancer with every weapon available to us. Early detection and immediate, proper health care are the strongest weapons we have.

I hope, Mr. Chairman, we will mark up and vote on this bill as quickly as we possibly can.

Mr. BILIRAKIS. Thank you. The gentleman's time is expired. Mr. Bryant.

Mr. BRYANT. Thank you, Mr. Chairman. Thank you for scheduling this hearing. And as we all know, the Breast and Cervical Cancer Mortality Prevention Act of 1990 does not authorize the CDC to pay for treatment of breast and cervical cancer. However, as a condition of participation in the screening program, CDC requires that a participating State, territory and tribal program certify that the treatment will be offered to all women who have been diagnosed with cancer through this program.

CDC does not believe that any women are failing to receive treatment under the program. According to Dr. Lee, the director of the screening program at CDC, participating governments are required to initiate treatment within 30 days. According to CDC's data, a set of some 2 million women screened, 90 percent of the women initiate treatment within 10 days of diagnosis, well within the required 30-day period.

Also according to CDC, participating State programs have been determined and creative in ensuring that treatment services are available for women diagnosed with breast cancer or cervical abnormalities.

The availability of treatment sources reflects the extent of the State and local government support, the generosity of medical providers and the commitment of communities.

With those statements, I will say also that I am very pleased to sit next to Mr. Lazio and with his introduction of this bill. And I think this discussion that we have heard briefly through some of the statements of Dr. Lee, together with Mr. Lazio's bill, certainly give us an opportunity to really listen carefully today to what all the witnesses have to say. I for one am very excited and interested
to hear all of these witnesses, because I think we need to learn
more about this and I think react very quickly.

But again I look forward to especially Dr. Lee’s testimony, rep-
resenting the CDC today, but, again, thank Mr. Lazio for his good
bill, and I would yield back my time.

Mr. BILIRAKIS. I thank the gentleman. Mr. Dingell an opening
statement.

Mr. DINGELL. Mr. Chairman, thank you. First, I wish to thank
you for holding this hearing on H.R. 1070, the Breast Cancer and
Cervical Cancer Treatment Act of 1999. Its principal sponsors, Mr.
Lazio and Ms. Eshoo, deserve particular commendation. Certainly
Ms. Eshoo has demonstrated remarkable leadership and commit-
ment in the sponsorship of this bill, which now boasts a total of 260
cosponsors.

Her persistence and effort have led directly to this hearing today,
and I think we should salute her for it. All of us are familiar with
personal stories of women who have suffered from breast or cer-
vical cancer, and we are aware of the difficult and painful process
these women face upon learning their diagnosis.

As someone who has lost family and friends to this terrible condi-
tion, I can well appreciate how all must feel. Imagine how much
more difficult the situation is for a woman who has been diagnosed
with breast or cervical cancer but doesn’t know when, where or
how she will obtain the needed medical treatment to save her life
because she has no health insurance.

These women are forced to expend precious energy searching for
doctors and hospitals willing to accept their charity case instead of
focusing on getting well. In today’s health care system, which is
dominated by managed care and fiscal constraints, there is no
guarantee whatsoever that these women or anyone else who is un-
insured will be able to obtain uncompensated care.

This legislation is a very important step in response to the need
of uninsured women diagnosed with breast and cervical cancer. I
urge speedy action so that we can help minimize the fear and un-
certainty that these women face each day in finding someone to
help them with the payments for their treatment.

I thank you, Mr. Chairman, and I yield back the balance of my
time.

Mr. BILIRAKIS. I thank the gentleman. Let us see. Dr. Coburn.

Mr. COBURN. Thank you, Mr. Chairman. This is an issue that I
have both a tremendous professional involvement in but also per-
sonal involvement. Every family in this country is or will be
touched by breast cancer and early diagnosis does not always make
the difference unfortunately. This bill that Ms. Eshoo, Mr. Lazio
have put together is a necessary bill. I have some concerns about
the bill that I have addressed with Mr. Lazio in terms of the abuse
of the insurance industry using title XIX now for pregnancy, that
I want to make sure is not available to be abused under title XIX
as we go forward with this bill.

But even more than that, I am angry with the CDC because they
have done nothing to prevent cervical cancer. They help diagnose
it, but 94 percent of all cervical cancer is associated with human
papilloma virus, which is not a reportable disease and they have
refused to make it such.
They have refused to educate the American public on this disease. They have refused to admit that a condom offers no protection for it. They have refused to do what their charge is, to prevent this disease. And although not nearly so many women die from cervical cancer as do from breast cancer, the trauma, the procedures that they must go through and the long-term sequela are often-times just as great and just as emotionally debilitating.

So I look forward to talking with Dr. Lee about that issue. I am supportive of this bill with the changes that I hope can be made to it. And I am hopeful that we will continue to treat not just breast cancer and cervical cancer, but all the other maladies that we can prevent for those that don't have access, that we can make access available to them. And with that, I would say that I would hope that this full committee and the Subcommittee on Health will give great credence to John Shadegg's bill on access to care, because it has been estimated to increase insurance coverage for 7 to 12 million people today who do not have coverage.

And I would just like to finish with a tribute to a lady by the name of Sharon Wetz. She was diagnosed with breast cancer, early diagnosis, in 1980. She had no metastases. She had a modified radical breast dissection, and two summers ago had a recurrence of her disease and had every available treatment offered today. She died 2 months ago. Ironically, she spent her whole life helping women with breast cancer before she was diagnosed. This is a disease we must beat.

And I thank you, Mr. Chairman.

Mr. BILIRAKIS. I thank you, Dr. Coburn. Ms. Eshoo.

Ms. ESHTOO. Thank you, Mr. Chairman. First I want to express my deep appreciation to you for holding this hearing on the bill and for your cosponsorship. Both are very, very important signals, not just within the Congress, but across the country to so many that want and need to have something done. So I want to pay tribute to you first and equal tribute to my colleague, Rick Lazio, because he was the first one to step up to home plate. He then came and found me, and off we went.

I would also like to pay tribute to all of the members of the subcommittee and members of the full committee who are cosponsors of H.R. 1070. About 75 percent of members of both are cosponsors of this bill. So there is solid support from both sides of the aisle. And I think that when we craft something together, that it not only gives increasing hope to the American people, but it fuels the effort because it is not easy to get something through the Congress of the United States.

I also want to pay tribute to all of the organizations that have come in and around this, that have helped with the bill, that have met with members. Whether they have endorsed the bill or not, they have still been partners with us. And to that end, Mr. Chairman, I would like unanimous consent to submit for the record of this hearing organizations that have written letters of endorsement. There are many. The American Cancer Society, National Women’s Health Network, the Maine Breast Cancer Coalition, the County of San Mateo California, the San Mateo Health Services Agency of California, the California Breast Cancer Organization, the Cancer Research Foundation of America, the National Associa-
tion of Public Hospitals and Health Systems and the California Association of Public Hospitals and Health Systems.

Mr. BILIRAKIS. Without objection.

[The following was received for the record:]

AMERICAN CANCER SOCIETY
NATIONAL GOVERNMENT RELATIONS OFFICE
March 18, 1999

The Honorable RICK LAZIO
United States House of Representatives
Washington, DC 20515

The Honorable ANNA ESHOO
United States House of Representatives
Washington, DC 20515

DEAR REPRESENTATIVES: The American Cancer Society, representing more than 2 million volunteers, supports the Breast and Cervical Cancer Treatment Act of 1999. We appreciate your sponsoring this important legislation which will allow states the option of providing Medicaid coverage for breast and cervical cancer-related treatment services to women who have been diagnosed with breast and cervical cancer through the National Breast and Cervical Cancer Early Detection Program.

Breast and cervical cancer will kill more than one-half million women in the 1990’s. Almost all deaths from cervical cancer and more than 30% of deaths from breast cancer in women over age 50 could be prevented by early detection (through widespread use of Pap tests and mammograms) and prompt treatment.

Since the inception of this program, more than 1.5 million screenings have been provided to eligible women resulting in the diagnosis of more than 3,600 women with breast cancer, approximately 26,000 women with cervical neoplasia, and over 400 women with invasive cervical cancer.

Through March of 1996, approximately 96% of the women diagnosed with cancer as a result of the program had initiated therapy. States have creatively developed or funded a variety of creative approaches to treatment, blending together a range of strategies that include use of public hospitals, access to county indigent care funds, access to hospital community-benefit programs, provider generosity, and individually negotiated payment plans.

As the States screen more women, and more cancers are diagnosed, ensuring care for all who need it will place increasing stress on fragile and overburdened treatment systems. Long term solutions for ensuring treatment are needed. By setting up a treatment option, this legislation will free up resources (time and money) so that case and program managers can focus efforts on bringing more women into the program to take advantage of early cancer screenings.

In the meantime, the NBCCEDP must continue to reach out to women who do not routinely seek health care services and may only be reached by the services offered under this important program. State programs are reaching only 12-15% of the women eligible for services in each state. All women in this country deserve access to quality health care. We must fund NBCCEDP at $215 million and pass your important legislation if we are to move toward that goal.

We applaud your efforts to address this serious health care challenge and look forward to working with you to secure passage this year.

Sincerely,

KERRIE B. WILSON
National Vice-President, Policy Advocacy

NATIONAL WOMEN’S HEALTH NETWORK
March 17, 1999

The Honorable ANNA ESHOO
U.S. House of Representatives
Washington, DC 20515

DEAR REPRESENTATIVE ESHOO: I am writing to thank you for your sponsorship of the Centers for Disease Control and Prevention (CDC) Breast and Cervical Cancer Treatment Act. The National Women’s Health Network has endorsed the bill because we believe it will offer critical access to services for uninsured women with breast and cervical cancer.

As you know, the CDC Early Detection Program screens tens of thousands of women for breast and cervical cancer each year. It is an important contribution to
the health of women in this country, but screening is only the first step for women who receive a cancer diagnosis. What those women must face next is cancer treatment, and women who do not have health insurance face a battle to find a way to pay for their treatment. The Breast and Cervical Cancer Treatment Act will ensure that women who are diagnosed with cancer through the CDC Early Detection Program have access to the treatment services they need. It will ensure that the U.S. government does not provide a woman with a diagnosis of a life-threatening illness and then abandon her, without access to health care, to deal with the consequences on her own.

The National Women's Health Network is an independent, member-supported organization dedicated to safeguarding women's health rights and interests. The Network advocates for better policies on women's health and provides women with information and resources to assist them in making better health care decisions. Nationwide, the Network has more than 12,000 individual members and 300 organizational members.

The Network is pleased to have the opportunity to work with you to gain the support of your colleagues and to achieve passage of the CDC Breast and Cervical Cancer Treatment Act. Thank you again for your vision and your leadership on behalf of the health of U.S. women.

Sincerely,

CYNTHIA PEARSON
Executive Director

MAINE BREAST CANCER COALITION
March 29, 1999

The Honorable ANNA ESHOO
U.S. House of Representatives
Washington, DC 20515

DEAR REPRESENTATIVE ESHOO: The Maine Breast Cancer Coalition strongly endorses the Medicaid Breast and Cervical Cancer Treatment Act, H.R. 1070. This proposed legislation will provide a critically important treatment program to the CDC Breast and Cervical Cancer Early Detection Program.

The Maine Breast Cancer Coalition thanks you for all your efforts on behalf of our mission to eradicate breast cancer. We look forward to your continued support and appreciate your dedication to this issue.

Sincerely,

LINDA J. MORNEAULT
President, MBCC
LAUREL BEZANSON
Advocacy Chair, MBCC
NBCC State Coordinator

COUNTY OF SAN MATEO
BOARD OF SUPERVISORS
July 13, 1999

Honorable ANNA ESHOO
14th Congressional District
205 Cannon House Office Building
Washington, D.C. 20515

DEAR CONGRESSWOMAN ESHOO: On behalf of the San Mateo County Board of Supervisors congratulations on your great success in securing a hearing to extend Medicaid coverage to the uninsured working and poor women for breast and cervical cancer treatment. We applaud your tenacity and your commitment to bring forward this important health care policy.

As you know, in California approximately 5,000 women will die of breast cancer and nearly 20,000 new cases will be diagnosed in 1999. What's more, it is reported that in California the highest incidence of breast cancer is found in Anglo-women, yet the highest mortality rate occurs among African-American women and the largest percentage of late-stage diagnosis occurs among Latino and African-American women. All of the increased funding directed at prevention, education and early detection is lost when not accompanied by access to treatment.

The San Mateo County Board of Supervisors is pleased to provide you with any information, documentation or data that you deem useful to you at the July 21, 1999 House Commerce Committee, Subcommittee on Health and the Environment.
If there is any beneficial experience that can be found in San Mateo County’s long-history of providing health care to thousands of uninsured and underinsured working and poor through the San Mateo County General Hospital, our system of community-based clinics or the provision of the San Mateo County Health Plan, that will assist you in making the case to extend Medicaid coverage for the treatment of breast and cervical cancer, please do not hesitate to contact me. The Board of Supervisors enthusiastically extends the County’s resources and appropriate expertise to the success of your effort. We look forward to working with you on this important issue.

Sincerely,

ROSE JACOBS GIBSON
4th District Supervisor

cc: Honorable Members, Board of Supervisors
    Karen Chapman, District Chief-of-Staff, Congresswoman Eshoo’s Office
    John Maltbie, County Manager
    Mary McMillan, County Legislative Director
    Margaret Taylor, County Health Services Director.
    Frank Gibson, Hospital Consortium

HEALTH SERVICES AGENCY
COUNTY OF SAN MATEO
July 7, 1999

Honorable ANNA ESHOO
14th Congressional District
699 Emerson Street
Palo Alto, CA 94301

DEAR CONGRESSWOMAN ESHOO: I want to thank you for your extraordinary efforts to allow women suffering from breast or cervical cancer to receive Medicaid coverage. On behalf of the staff and patients at San Mateo County General Hospital and Clinics, I want to let you know how much we support this proposed legislation. San Mateo County is comprised of a large number of residents who lack health insurance. Many of these individuals are the working poor who earn either too much money to qualify for Medi-Cal or too little money to pay for private insurance. This lack of coverage and resources has become particularly worrisome for our female residents who develop breast or cervical cancer. These women delay physical check-ups and treatment due to their inability to pay. By allowing these women to receive Medicaid coverage, they will have a chance to seek the treatment they need to combat this terrible disease.

Adoption of this legislation would be very beneficial to the communities we serve. Thank you for all your hard work and dedication to undeserved women in this county.

Sincerely

MARGARET TAYLOR,
Director, Health Services Agency

cc: Hospital Board of Directors
    Mary McMillan, Legislative Director

CALIFORNIA BREAST CANCER ORGANIZATIONS
April 21, 1999

The Honorable DUNCAN HUNTER
2265 Rayburn HOB
Washington, DC 20515-0552

DEAR CONGRESSMAN HUNTER: The California Breast Cancer Organizations (CABCO) was started in 1991 by women with breast cancer. Since then, CABCO has provided a forum for individual organizations to come together to represent thousands of breast cancer survivors, their families and friends. CABCO member organizations inform, support, and advocate to better the health of California women diagnosed and living with breast cancer.

CABCO member organizations, representing many of your constituents, is hereby urging you to join your colleagues from California and over 100 members of Congress and be a cosponsor for the Breast and Cervical Cancer Treatment Act (H.R. 1070). For your information, we have enclosed a copy of the letter.

Take action now and give the gift of life to women around the country by cosponsoring this very important legislation. Call Congresswomen Eshoo (202-225-8104) or
Capps (202-225-3601) and Congressman Brian Bilbray at (202-225-2040) to include your name NOW.

We cannot afford to screen underserved and underinsured women and men for life-threatening diseases without finishing the job—this means establishing a treatment program that will assure them of access to the necessary medical care to treat their disease. It is unconscionable and inhumane to screen for a disease like breast cancer, be diagnosed with it and be told, “Sorry, but we don’t have a treatment component to this program. You are on your own.” How would you like to be one of them?

CANCER RESEARCH FOUNDATION OF AMERICA
ALEXANDRIA VA
March 19, 1999

Congresswoman ANNA ESHOO
205 Cannon House Office Building
Washington, DC 20515

DEAR CONGRESSWOMAN ESHOO: On behalf of the Cancer Research Foundation of America (CRFA), I would like to express my strong support for H.R. 1070, legislation to provide treatment assistance for women without health insurance diagnosed with breast or cervical cancer under a federally funded screening program.

As a Foundation that funds several local programs to screen women for breast and cervical cancer, including the George Washington University Mobile Mammography Van and Celebremos La Vida!, we feel strongly that treatment of any cancer detected through our programs must be offered if the woman does not have health insurance available to her.

We strongly support the legislation that you have introduced, which will apply these same standards to the Centers for Disease Control and Prevention breast and cervical cancer early detection program.

CRFA would be pleased to work with you and your staff towards passage of this important legislation. Please do not hesitate to call on Lisa Hughes, or me at 703-836-4412 if we can be of assistance.

Sincerely,

CAROLYN ALDIGE
President and Founder

NATIONAL ASSOCIATION OF PUBLIC HOSPITALS & HEALTH SYSTEMS
March 16, 1999

The Honorable ANNA ESHOO
The United States House of Representatives
Washington, DC 20515

DEAR ANNA: I am writing on behalf of the National Association of Public Hospitals & Health Systems (NAPH) to express our support for H.R. 1070, which would provide Medicaid coverage for uninsured low-income women screened and found to have breast or cervical cancer under the CDC’s screening program. NAPH represents over 100 metropolitan area safety net hospitals and health systems. As safety net institutions, our members are essential providers of care to uninsured and vulnerable populations whose access would otherwise be severely constricted. Over 65 percent of the patients served by these systems are either Medicaid recipients or Medicare beneficiaries. Another 25 percent are uninsured.

NAPH strongly supports all efforts to expand health care coverage for America’s uninsured. Under present law, the CDC’s early detection program provides a critical service in identifying women who have cancer and require treatment. However, without coverage for such treatment, uninsured women who know they have cancer face difficult barriers in receiving and paying for treatment for their condition. Your proposed legislation would directly address this issue by providing health coverage for low-income women diagnosed with breast or cervical cancer who do not otherwise have health coverage. This would greatly enhance the effectiveness of the CDC program and provide a great benefit for uninsured women with a serious medical condition.
We look forward to working with you further to develop legislative solutions to the problems of our nation's poor and uninsured. If you have questions about this letter, please contact Charles Lubinsky at 202/624-7215.

Sincerely,

LARRY S. GAGE
President

CALIFORNIA ASSOCIATION OF PUBLIC HOSPITALS AND HEALTH SYSTEMS
July 19, 1999

The Honorable ANNA ESHOO
205 Cannon House Building
Washington, D.C. 20515

DEAR REPRESENTATIVE ESHOO: On behalf of the California Association of Public Hospitals and Health Systems, I would like to express our strong support of your legislation, H.R. 1070. This bill would give states the option to provide Medicaid coverage to uninsured women who have been diagnosed with breast or cervical cancer through the National Breast and Cervical Cancer Early Detection Program.

Studies have shown that routine screening for breast and cervical cancer coupled with timely treatment can reduce deaths from breast cancer by 30% and can almost entirely prevent the onset of cervical cancer. As public health care providers, our members screen thousands of low-income women each month for breast and cervical cancer. While California has implemented a very effective screening program through the CDC-funded Breast and Cervical Cancer Control Program as well as through a state-funded program, there are far fewer resources available to finance treatment for low-income uninsured women, once they've been diagnosed. Since 1991, more than 1,100 low-income women have been diagnosed with breast or cervical cancer and referred for treatment, although most had no way to pay for their care.

California has attempted to address this problem by creating a Breast Cancer Treatment Fund, which is supported by private foundation and state general fund dollars. However, this is not a permanent program, and it has been at risk of being de-funded in each of its two years of operation. A total of 411 women have received assistance through the Fund, with grants averaging $7,623 per case, although these grants often do not cover the full range of services needed by women. Unfortunately, there is no similar statewide treatment program for low-income women with cervical cancer.

As a result, many of these uninsured women seek care from our county hospitals, often times at a later stage of disease than if health insurance coverage were available to pay for their treatment. Enabling low-income women who have been diagnosed with breast or cervical cancer to become eligible for Medicaid would help ensure that they receive timely treatment, which is essential for a successful outcome. Moreover, such coverage would help cover significant unreimbursed costs incurred by county hospitals in California in providing such treatment. As you know, our hospitals are already stretched tight due to shrinking indigent care funding and the growing number of uninsured in California.

We applaud your efforts in authoring this important bill and your ongoing leadership regarding all health issues, particularly for low-income populations.

Sincerely,

DENISE K. MARTIN
President & CEO

cc: CAPH Board Members

Ms. ESHOO. Thank you. As Mr. Lazio explained just a few minutes ago, when we held our press conference in the Capitol to announce the introduction of our bill, we were very, very proud that day. I think that there were something like 50 or 60 cosponsors of the bill. We did make a promise that we would do everything that we could to secure the majority of the House of Representatives by Mother’s Day, because we wanted to continue to send out a signal of some hope in the country. When all is said and done, truth be known, this is not a large bill, this is not a bill that is directed toward curing breast and cervical cancer.
It doesn’t make a gigantic promise to people across the country, so we need to keep it in context. And you may be surprised that as the original Democratic cosponsor that I am saying this. But I do think that within that context that we need to develop the political will to get this done. We should not be in the business of saying that we will only go halfway with people. The Federal Government, through an excellent program that it directed the CDC to undertake, the program of screening, was established by the Congress before either Mr. Lazio or I arrived in the House of Representatives. We are going to hear more about that.

We need to take the next step. We shouldn’t be in the business of saying to women and their families, you don’t get treatment because you are underinsured or uninsured. We all have these women in our districts. And with all due respect to the agencies that implement the programs who are our partners in public service, we play a different role in America. Why? Because we are with our constituents every week.

I fly across the country to California, as my colleagues fly or drive or take the train to their districts, and I know what my constituents say to me. This is not something that is fabricated. They have needs, and they come to us as their representatives, not only to be their eyes and ears, but to take action on their behalf.

I think the greatest, most powerful nation on the face of this Earth can do better. We can do better, and we should do better, and we should stand next to these families that really need the kind of help and not take them halfway and go the entire route.

There is someone—Mr. Chairman, I request just a minute longer.

Mr. BILIRAKIS. Without objection.

Ms. ESHOO. Thank you very, very much. I have pages here of statistics that I will submit with my formal statement. I would like to point out that there is someone here this morning that the National Breast Cancer Coalition was very generous in helping to come to Washington. She is seated in the second row, and her name is Josefina Mondada from Texas.

She was diagnosed in September 1998. She was working but uninsured. She discovered a lump and she was screened. The diagnosis informed her that she had cancer and needed treatment. There was one doctor 1 hour away from her. There were a few more doctors 5 to 6 hours away from her. She took care of her ill husband, which is very often the case with American women. When we take something new on, we don’t give up other responsibilities, which makes it all the more difficult for women to take on that additional responsibility.

So, Josefina, thank you for coming all the way to Washington. I think that you are a very powerful presence for many women and their families around the country.

And, Mr. Chairman, I hope that after today’s hearing that we will continue to demonstrate our political will to take a very important small bill and an even larger step forward in fighting breast and cervical cancer.

Yesterday I believe was the 30th anniversary of placing the first man on the moon. Now if we could do that 30 years ago, we sure as hell can do this one in the Congress in this session. So I want to thank all of my colleagues for what they have chosen to do.
will do everything that I can to work with anyone that has ques-
tions about how we can do this even better. But I think that we
need to do it. So I know I don't have any time left to relinquish,
but I thank you for giving me the additional time.

Mr. BILIRAKIS. I thank the gentlelady.

Mr. Waxman.

Mr. WAXMAN. Thank you very much, Mr. Chairman. I am ex-
tremely pleased that this subcommittee is having this hearing
today. I am a proud cosponsor of the Lazio-Eshoo bill. I strongly
support it. I chaired this subcommittee when we originally passed
the breast and cervical cancer screening program. It was an impor-
tant step forward, and I believe it has been a real success story.
But now the time has come to take the additional step of providing
Federal support through the Medicaid program to secure the nec-
essary treatment and follow-up services to those women who have
breast or cervical cancer uncovered through this very same screen-
ing program.

Let me say that I think CDC and its grantees have done a yeo-
man’s job of responding to the directive in the law that they ar-
range for services for women who have breast or cervical cancer
discovered through the screening, but this is far from ideal as a
way of assuring these women services. Depending on the avail-
ability of charity care to see that these conditions are treated is
necessarily going to be a difficult process, and we run the serious
risk that it will be inadequate to the problem.

We subject these women to the trauma of the uncertainty of
whether care will be available. We run the risk that follow-up
treatment does not occur. We probably even lose some people who
are reluctant to be screened when they know they do not have in-
surance if treatment is needed. This bill would change that, and it
makes a great deal of sense to me. It gives the States the option
to extend Medicaid coverage to the women when cancer is discov-
ered.

It says that the Federal Government will be a partner in paying
for their treatment. I know every one of us in Washington shares
the feeling of frustration when we have to try to explain to our con-
stituents why we have a program that defies common sense. How
can we screen women for these conditions and then when we find
them fail to pay for the care that is needed?

When we developed the screening program, that was all we could
do. But we took the first steps. It remains a law that I am proud
of. Now nearly a decade has passed since that landmark bill. We
know screening for this population works. Surely the time has
come to take the next step and pay for treatment services. Let us
rationalize our policy and do the right thing.

Thank you, Mr. Chairman.

Mr. BILIRAKIS. I thank the gentleman.

Mr. Green, an opening statement.

Mr. GREEN. Thank you, Mr. Chairman. And like my colleagues
I am proud to be a cosponsor of H.R. 1070, the Breast and Cervical
Cancer Treatment Act, and as of today we have 263 cosponsors,
which is a credit not only to my colleague from New York, but also
to my colleague from California. When Congress passed the Breast
and Cervical Cancer Mortality Prevention Act in 1990, we only did
part of the job. As we learned, screening for cancer is only useful if there is a treatment available to back it up.

And while statistics show that treatment has been available to most of the women who have been screened through the early detection program, I think the broad support of this bill demonstrates the need to improve this critical phase. Some problems with the existing program include long waiting times for treatment, which can be life threatening, inconsistency of care and dwindling resources of physicians who are willing or can afford to continue to donate their services.

Moreover, the mental strain on a family when a loved one is diagnosed with cancer is simply overwhelming. To add the uncertainty of not knowing where to find or if you will find treatment is just too much to put on these families. H.R. 1070 will solve some of these problems, as my colleagues have said, by working for women diagnosed with breast or cervical cancer through the early detection program eligible for Medicaid for the duration of their treatment.

And I think it is appropriate on a day when the House is going to consider an $800 million tax cut bill, hopefully we can afford to pass this legislation.

Thank you, Mr. Chairman. I yield back my time.

Mr. BILIRAKIS. I thank the gentleman. Dr. Ganske, do you have an opening statement?

Mr. GANSKE. No, Mr. Chairman.

Mr. BILIRAKIS. Mr. Barrett, do you have an opening statement.

Mr. BARRETT. I do not.

[Additional statements submitted for the record follow:]

PREPARED STATEMENT OF HON. CLIFF STEARNS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF FLORIDA

Mr. Chairman, thank you for holding this hearing today on H.R. 1070, legislation to provide medical assistance for certain women screened and found to have breast or cervical cancer under the Center for Disease Control's Early Detection Program.

As we know, breast cancer is both scary and frightening to many women. Tragically, this disease strikes one out of every eight women today. Less than a decade ago it was one out of every ten women. We must find a way to eradicate this disease which causes women so much trauma in their lives. The physical and emotional pain is practically unequaled.

The statistics bear out why this disease is so dreaded. This year alone there will be an estimated 175,000 new cases diagnosed and more than 43,000 women will die as a result of this dreaded disease.

The Center for Disease Control has classified breast cancer as a chronic epidemic. If detected early, the survival rate is almost 100%. We need to make early detection a top priority.

When we think about the various cancers that can afflict women, we rarely focus on cervical cancer. Yet, 2-3 percent of all women over the age of 40 will develop some form of cervical cancer. That translates to about 5,000 deaths per year.

The good news is that routine pap smears are very effective in detecting abnormal cells and if detected in time can be treated with promising results. Because there are no discernible symptoms in the early stages, it is vital that women see their physician on an annual basis since early intervention with proper treatment can save 80% of women. Once this disease progresses and spreads to other organs the survival rate drops significantly.

We know from data provided by CDC that 90 percent of women screened initiated treatment within 10 days of diagnosis which is well under the required 30 day period.

I look forward to hearing from our witnesses about the merits of expanding coverage under this program to women who are not poor enough to qualify under Medicaid and too young to qualify under Medicare.
Thank you, Chairman Bilirakis, for this important hearing this morning on Mr. Lazio's bipartisan proposal to expand Medicaid coverage to those women who have been screened and diagnosed to have breast or cervical cancer through the National Breast and Cervical Cancer Early Detection Program, which is administered by the Centers for Disease Control and Prevention.

As many of you know, breast and cervical cancer is a matter of great concern to me. My wife is a breast cancer survivor. In the last Congress, I worked with Chairman Bilirakis to pass The Mammography Quality Standards Reauthorization Act of 1998, which now requires that written notification of test results be sent directly to the patient. We have encouraged mammography facilities to urge their patients to follow up with their own physicians.

We also successfully bolstered the CDC breast and cervical cancer screening program by enacting into law the Women's Health Research and Prevention Amendments of 1998, which authorizes CDC to increase its assistance to state, territorial, and tribal governments for case management services. Since CDC requires that all the women screened with cancer will be offered treatment in their own states, I believe that this new authority will help many uninsured women in this program more quickly find treatment in their community.

As we listen to the testimony today, let me remind my colleagues that the core matter before us is the fact that all of the women in this program are uninsured. If we can move on market-based reforms in this Congress on a bipartisan basis, we will be helping those women who are presently covered by the CDC screening program. Let me also remind us all of a few facts about the uninsured:

- The quality and affordability of health coverage for all Americans is directly linked to consumers exercising choice in the health care market place. We should not assume there has to be a trade-off between having quality health coverage and affordable health coverage—you marry quality and affordability when you seek value, which is the best possible coverage and the best price.
- Mandates on health insurance add costs to premiums and may have the unintended consequence of impeding access to necessary health coverage for many Americans, just as many women who discover they have cancer are without insurance coverage.
- We also know that the tax code discriminates against the waitress at the corner diner and the sales clerk whose employers are unable to provide them with health coverage. Employer-purchased health coverage is 100 percent tax free to the employer and employee, but you are out of luck if your employer cannot provide you that coverage.

What many Americans are missing today is a place to shop for affordable health coverage that meets the needs of their families.

The goal of my HealthMart proposal, which I am working with the minority to enact into law, is to give employees options within today's job-based health care system. To do so, however, we must address the impediments in the marketplace that add cost and make it difficult for the small business person to afford coverage for his or her employees.

As we listen to the testimony today, I ask my colleagues to consider not only the reforms that may be necessary to the CDC breast and cervical cancer screening program, but also the need to enact HealthMarts and other market reforms to increase affordable insurance coverage for all Americans.

Thank you Mr. Chairman. As a cosponsor of H.R. 1070, I want to thank you for holding today's hearing on this important legislation. I appreciate your leadership on this issue, and look forward to working with the majority to mark-up this bill. I would also like to thank my colleagues Ms. Eshoo and Mr. Lazio for their tireless leadership on behalf of this legislation.

Since the inception of the Centers for Disease Control's National Breast and Cervical Cancer Early Detection Program, over 1.2 million women have been screened for these diseases. In my home state of Colorado, 28,300 women received mammograms and the program provided 37,056 pap tests. Despite these achievements, the program is still only able to reach 15 percent of the eligible population. This number is unacceptable. We would never accept that only 15 percent of our children were vaccinated by a public health campaign and we should not be satisfied that only 15 percent of women are being screened for breast and cervical cancer. This program MUST grow and H.R. 1070 would enable it to do so.
This Committee must be pro-active. The success of the Early Detection Programs illustrates the critical role public health programs play in low-income communities. At a time when health care disparities are widening on racial lines, these programs have eliminated the disparities between black women and white women in terms of breast and cervical cancer screening. By detecting breast and cervical cancer early, the screening program saves lives and health care costs. A woman participating in an Early Detection Program has a better chance of beating her cancer at a much lower personal and financial cost. If she were not screened through the CDC program, she would be diagnosed, most likely but much later, after her disease had progressed to a much more disabling point. Treatment would be much more costly, and most importantly, she would be at much greater risk of dying from her disease.

The program is a victim of its own success which illustrates the need to expand the program to include coverage for treatment once a cancer is detected. Ninety percent of all women diagnosed with cancer under this program receive treatment because many state programs have been creative in ensuring that treatment services are available for these women. Often, these women rely on the resourcefulness of the screening program’s employees and the generosity of doctors and their communities to receive the treatment they need. This is a tenuous system at best and, states will only be able to “shake the tin cup” for so long. As more women are screened by the National Breast and Cervical Cancer Early Detection Program, it will be more difficult for women to obtain the treatment they need.

It is time for Congress to act and ensure that any woman found to have cancer under this program would have access to treatment. Now, women who need and want cancer treatment receive it. However, Congress must be foresighted. Without a guaranteed treatment option, screening programs will have to devote more of their resources to locating treatment options, which means fewer women will be screened. This is clearly the wrong direction since only 15 percent of eligible women are being screened currently.

I look forward to today’s hearing and to working with this Committee to ensure that we pass legislation, which will strengthen the National Breast and Cervical Cancer Early Detection Program. I yield back the balance of my time.

Mr. BILIRAKIS. All right, thank you. I think that takes care of the opening statements. Of course, as per usual, the opening oral statements and written statements of all members of the subcommittee are made a part of the record.

Now we will call the first panel, which consists of Dr. Nancy C. Lee, Director of the Division of Cancer Prevention and Control, Centers for Disease Control in Atlanta, Georgia.

Dr. Lee, as I said earlier, we welcome you here. Nice to see you in our bailiwick, as we were in yours a few weeks ago. Ordinarily we limit witnesses to 5 minutes, however since you are the administration witness we are going to allow you to have 10 minutes. And, you know, we will be flexible there.

Ms. Lee. Okay.

Mr. BILIRAKIS. Your written statement is a part of the record. So you can either read from that or just supplement the full statement. Please proceed.

Ms. Lee. Thank you.

Mr. BILIRAKIS. Thank you.

STATEMENT OF NANCY C. LEE, DIRECTOR, DIVISION OF CANCER PREVENTION AND CONTROL, CENTERS FOR DISEASE CONTROL

Ms. Lee. Good morning. As you said, I am Dr. Nancy Lee, Director of the Division of Cancer Prevention and Control at the Centers for Disease Control and Prevention. I am pleased to be here this morning to discuss CDC’s National Breast and Cervical Cancer Early Detection Program.

In 1990, Congress passed the Breast and Cervical Cancer Mortality Prevention Act. Now, CDC is in the ninth year of the pro-
gram, which brings breast and cervical cancer screening services to underserved women, including older women, women with low incomes, and women of racial and ethnic minorities.

CDC supports early detection programs in all 50 States, five U.S. Territories, the District of Columbia and 15 American Indian and Alaskan native organizations. The program establishes or expands community-based screening services to reduce breast and cervical cancer mortality.

The success of the program depends on screening, education and outreach, case management and mechanisms to assure the quality of tests and procedures. Also the women diagnosed with cancer and precancer need treatment—need to receive timely and appropriate treatment. And we are committed to all of those parts of our program.

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

We are not able to collect information on the type or quality of treatment received. Through September 1998, 1.3 million women have received 1 million Pap tests and 950,000 mammograms. Almost half of these screenings were to minority women. More than 5,800 women were diagnosed with breast cancer. More than 30,000 women were diagnosed with precancerous cervical lesions and 508 women had invasive cervical cancer.

The majority of these cancers have been diagnosed at an early stage. 27,000 health professionals are involved in providing breast and cervical cancer screening services to underserved women. More than 18,000 health educators and outreach workers are educating women on the importance of early detection, and one of CDC's partners in the program, Avon, has raised $32 million to educate women about breast cancer and provide underserved women with access to early detection services.

As we have already heard before this morning, screening exams by themselves do not save anyone's life; ensuring that all women with abnormal screening results receive adequate follow-up and a diagnosis is a crucial component of this program. Thus CDC's program supports breast diagnostic services including diagnosis mammography, breast ultrasound, fine needle aspiration and breast biopsy, and for the cervix coloscopy and biopsy.

Moreover, women diagnosed with breast cancer must receive timely and appropriate treatment. The legislation authorizing the national program does not allow Federal resources to be used for treatment; however, States are required under terms of the grants they receive to assure that women who are screened and need cancer treatment receive it. The most current program data indicate that 92 percent of the women diagnosed with breast or cervical cancer have initiated treatment, the remaining 8 percent refused the treatment, have not yet initiated or are lost to follow-up.

For women diagnosed with breast cancer, they show a median of 8 days between the cancer diagnosis and the initiation of treat-
A study of seven States' screening programs funded by CDC documents the approaches used to secure resources for treatment. Rarely is there a standard way to obtain treatment services for women who need them. State programs have developed sophisticated, creative, and successful strategies to deal with the challenge of payment for cancer treatment, and at least based on our data these so far have been working.

However, tremendous effort is involved in developing and maintaining these systems, and they are often tenuous, fragile and short lived. The following are some of the strategies that are employed by States to secure treatment services for women. Providers assist eligible clients in applying for Hill-Burton funds or other types of public assistance. Clients are referred to public hospitals or receive care through donated services or other charitable care. The program asks treatment providers through State and county medical societies to offer free or reduced cost services. Contracts with screening providers require that agreements with treatment providers be established before screening begins.

For example, North Carolina has appropriated State resources to provide for cancer treatment services for all State citizens who need eligibility criteria. California utilized a one-time allocation of $12.8 million from the Blue Cross Foundation to pay for treatment during the first year after diagnosis for eligible uninsured women.

Increases in CDC’s fiscal year 1999 appropriation will be used to expand critical case management services in States to strengthen the fragile system for securing treatment services. Each program will enhance case management activities to help clients to obtain treatment. CDC and its State partners will continue to give critical priority to the treatment issue, which is a critical aspect of the early detection effort.

Although States are currently meeting their commitment to help women access treatment, programs have told us of concerns regarding their ability to expand screening services to more women because the systems for obtaining charitable treatment are becoming overburdened. As long as the numbers of cancers diagnosed through the program remain near the current level, the burden should not be too great; however, increased screening, which is our goal, is accompanied by increased numbers of cancers diagnosed. And many physicians who contract with programs are concerned about bringing more uninsured patients into their care because of the need to provide treatment.

Lack of sources for treatment can lead to screening problems in States where screening providers must have standing treatment referral options in order to screen. CDC’s National Breast and Cervical Cancer Early Detection Program does not change whether a women has cancer. However, by improving her chances of detecting the cancer early and getting treatment for it, the program can help keep her from dying of it, and by finding and treating precancerous cervical lesions, the program prevents thousands of women from every developing cervical cancer.

Thank you. And I am happy to answer any questions you may have.

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

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

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

Through September of 1998, more than 2 million screening tests have been provided to over 1.3 million women. That number includes 1 million Pap tests and 950,000 mammograms. Almost half of these screenings were to minority women, who have traditionally had less access to these services. Over 5,000 women have been diagnosed with breast cancer, more than 30,000 women were diagnosed with precancerous cervical lesions, and 411 women had invasive cervical cancer.

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

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

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

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

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

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

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

A detailed study of seven state screening programs conducted by Battelle Centers for Public Health Research and Evaluation and the University of Michigan, funded by the CDC, documents the innovative approaches that have been implemented to identify and secure resources for treatment services. The study confirmed what we see in our Program data that arrangements for treatment were made for almost all clients who received a diagnosis of breast or cervical cancer. States' efforts to secure treatment for women screened through the Program have been further documented in a separate study conducted by the Susan G. Komen Breast Cancer Foundation. State programs and their partners have invested significant amounts of time and effort to develop systems of care for diagnostic follow-up and treatment; these systems appear to be working. However, tremendous effort is involved in developing, implementing, and maintaining strategies and systems for these services. Rarely is there a standardized way that a State, tribe or territory obtains treatment services women need that are not covered by the program. Efforts typically are tailored to an individual client's needs and resources.

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

- Providers assist eligible clients in applying for Medicaid, Hill Burton funds, or other types of public assistance.
- Clients may be referred to public hospitals, or receive care through hospital community benefit programs, donated services, or other charitable care.
- Contracts with screening providers require that agreements with treatment providers be established before screening commences.
- The Program appeals to treatment providers, through state and county medical societies and professional associations, to offer free or reduced-cost services to program clients.

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

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

Although States are currently meeting their commitment to help women access treatment services, several of the programs reviewed in the Battelle study expressed concerns regarding their ability to expand screening services to more women in need because the systems in place for obtaining charitable treatment are becoming overburdened. These programs stated that as long as the numbers of cancers diagnosed through the program remain near the current level, the burden should not be too great or too threatening.

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

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

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

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

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

Mr. BILIRAKIS. Well, thank you, Ms. Lee. During our visit to the CDC and in your written statement, you indicated the vast majority of patients screened are currently receiving treatment, but that the safety net is being stretched.

By your estimate, how many women screened through the program are not being treated?

Ms. Lee. Well, I think it is about 8 percent, but some of those are in the data pending category. So let me just check here. Our most current data suggests that 1 percent are lost to follow-up of the women diagnosed with cancer and 2 percent refuse care. About 5 percent, the information is pending. And I would assume the vast majority of those 5 percent will be destined at this point to receive care.

Mr. BILIRAKIS. In other words, information is pending.

Ms. Lee. Our data system has a lag time.

Mr. BILIRAKIS. You haven’t caught up to it yet?

Ms. Lee. Yeah, right. So the 2 percent refused care and the 1 percent lost to follow-up. And I might add that among both the refused and the lost to follow-up, extraordinary efforts are made to track these women down and to convert them to have—go ahead and have their treatment. Because we have this extensive data system and we have gotten a lot of feedback on this, it really enables the providers to find the women who might otherwise have fallen through the cracks. And they can really go after it with a vengeance and we know they do try to locate these women who have refused care or are lost to follow-up.

Mr. BILIRAKIS. I would like to get to that in a moment, because it blows my mind that people would refuse treatment. But on that 5 percent, will they receive treatment?

Ms. Lee. We don’t know.

Mr. BILIRAKIS. You don’t know?

Ms. Lee. I mean, that is information pending. It is a data lag. I would suspect that a number of them would just because it is 92 percent have received. It is just sort of—but it may be that the information is pending because they have lost the follow-up.

Mr. BILIRAKIS. Now does the CDC program require treatment?

Ms. Lee. Yes, in our grant awards, it is part of the grant award that the States in order to accept the money have systems in place to receive—to find treatment.

Mr. BILIRAKIS. This thought that some of the women who are screened and found to be positive are not receiving treatment is probably false, because in effect most women are receiving treatment unless they refuse it, right?
Ms. LEE. Or they are lost to follow-up. No, I think some women are not receiving treatment. And we don't know why they are refusing treatment.

Mr. BILIRAKIS. Will the 5 percent receive treatment within a certain number of days, say within 30 days?

Ms. LEE. Well, no, 92 percent of the women in our data set, which is currently through March 1998, we have a big lag time. But—because you know we have several million records in there, but through March 1998, 92 percent of women have initiated treatment. That is all we know. We do not know if it was a full course, they have initiated treatment. And then did. So there are 8 percent of women that we are not certain that they have, 3 percent basically have either refused or lost to follow-up.

Mr. BILIRAKIS. Okay. But the 5 percent—

Ms. LEE. That is just where the data are pending.

Mr. BILIRAKIS. Okay. But—

Ms. LEE. Some of them may fall into the refused or lost to follow-up.

Mr. BILIRAKIS. But those that will not fall into those, what is now the 3 percent category will be receiving treatment in a timely manner?

Ms. LEE. It may not be timely, but the timeliness is a separate item. We have information on every woman who is diagnosed, we have the date of diagnosis and the date the treatment was initiated. The median for that is 8 days, but there are women in our data set whose treatment was initiated over a year afterwards. So they are what we call in statistics the sort of the end of the curve.

Mr. BILIRAKIS. Okay. I am contemplating for the benefit of the members of the panel—

Mr. LAZIO. Mr. Chairman, was it a year that she said?

Ms. LEE. There are women in our data base—the median, half of the women receive their treatment initiation within 8 days. That is what median means, but there are women who are very far out. There are not very many of them or the median wouldn't be 8 days.

Mr. BILIRAKIS. Now, why are they far out?

Ms. LEE. For a whole variety of reasons, and we do not have the information in our data set as to why they are very far out.

Mr. BILIRAKIS. All right. I just wanted to announce that my contemplation is we would have a second round so we can maybe cover these things with the doctor provided she is willing. And I would like to think she is.

Ms. LEE. I do have a plane to catch to San Diego.

Mr. BILIRAKIS. What time?

Ms. LEE. Three something, and I have a conference call before then.

Mr. BILIRAKIS. We have got to vacate this room by 2 o'clock.

Ms. LEE. Everybody has got to eat lunch too, right?

Mr. BILIRAKIS. Let me ask you, Doctor, just one general question. I suppose the bottom line is trying to help as many women who need help as possible. But we have got to find the people who need the help, in other words, screening first. We can have the best treatment methods on God's earth, but if we can't get to those who need it we can't help them, right?

Ms. LEE. Exactly.
Mr. BILIRAKIS. Maybe you can address the screening aspect for us very briefly. Now that is not the subject of this legislation, but can you address this issue? I mean is there something that can be done reasonably and responsibly to improve that area, or would you feel that there isn't much more that we can do; in other words, it just takes time to reach out?

Ms. LEE. Well, I mean the technology could always improve. That is not what we are about. You know, we are about taking and improving technology and applying it, but certainly that is one area that we could go, is to have improved technology for screening. And right now with our current resources, we can reach only 12 to 15 percent of eligible women.

Mr. BILIRAKIS. All right. I guess that is the point.

Ms. LEE. Yeah.

Mr. BILIRAKIS. So you know we can have the best treatment methods on God's earth, and I am a cosponsor of this legislation, and if we don't do this legislation, I hope that it is only because we are doing something better, whatever that might turn out to be, if in fact there is anything better, again, if we only reach 12 to 15 percent of the eligible population, then, neither screening nor treatment are available to the women in need.

Ms. LEE. We estimate that there are about 11 million eligible women, women eligible for this program in the United States who are not—

Mr. BILIRAKIS. Who are not being—

Ms. LEE. [continuing] enrolled in the program.

Mr. BILIRAKIS. My time is up. Mr. Brown.

Mr. BROWN. Thank you, Mr. Chairman. Let us pursue that half a million women there. Just understanding that the target population is 250 people, 250 percent of poverty that are not Medicare or Medicaid eligible; is that correct?

Ms. LEE. Well, the target population varies in each State. The max—I mean the highest percent of poverty is 250 percent. There are some States where the eligibility requires lower, like 100 percent of poverty. Some States you have to be 100 percent poverty or lower to be eligible. So the States set the eligibility criteria. The CDC has provided guidance that it has to be 250 percent or lower, but some States go lower than that.

Mr. BROWN. To include more people or—

Ms. LEE. Well, to include—well, it makes even more low income.

Mr. BROWN. Okay. 12 to 15 percent of the target population is screened, that number you had cited earlier. What is the percentage of people screened who test positive?

Ms. LEE. Well, it is a cascade. Ultimately—and it differs for breast and for cervical cancer. We estimate that less than 1 percent of all the women we screened ultimately are diagnosed with breast cancer. About, depending on sort of how you make the definitions, 7 to 10 percent of women will have an abnormal mammogram. But most of those women who have an abnormal mammogram are found not to have cancer.

Even fewer percentage of women who are screened for cervical cancer have—are found to have the disease, remember we have screened 1.2, about 1 million women for cervical cancer and have found 50 cases. But as I say to everybody, our goal is not to find
cervical cancer, our goal is to find precancerous lesions, treat and cure the women. And so we have found 30,000 cases of precancerous lesions which we treat.

We also found cervical cancer and treat that, but our main goal is to find the precancerous lesion so women never have cancer.

Mr. BROWN. Some 85 percent of the population is not screened apparently?

Ms. LEE. 85 percent of the eligible population.

Mr. BROWN. The eligibility target population. And my understanding is that some of the screening program's resources are consumed by the search for treatment, because those doing the screening spend a significant amount of time and resources looking for physicians and other health care providers to do free or low cost treatment, correct?

Ms. LEE. Some of our—yes, I mean our State programs and the providers are required to make sure that every woman with cancer is treated, and so they have to find treatment sources.

Mr. BROWN. And under Federal law, none of the screening money may be used for actual treatment, correct?

Ms. LEE. Correct.

Mr. BROWN. Although some of the screening money is diverted in a sense in terms of time and resources to find free care.

Ms. LEE. As you know, in the law, 60 percent of the appropriated money must be used for direct clinical services. We use that for payment for the screening and diagnostic tests. The other 40 percent may be used for other things like professional education, case management, professional administrative costs, but some States actually use more than 60 percent to pay for screening. It just depends.

Mr. BROWN. Mr. Chairman, there is a letter from Dr. Robert Brooks, who is the secretary of the department of health in your State, as you know, to Senator Connie Mack, pointing out some of these problems in the State of Florida, and I have no reason to believe that it is different anywhere else. It is getting more and more difficult as we screen people to find free care, especially with the squeeze in managed care and in taking away the options that physicians and other providers seem to have.

And I would like to first ask unanimous consent to include this in the record.

Mr. BILIRAKIS. Without objection.

[The letter referred to follows:]

DEPARTMENT OF HEALTH
TALLAHASSEE, FL
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 1996. The 20 counties are composed of large urban areas, mid-sized counties and small rural counties. (A map depicting all 20 participating counties is enclosed.) Population data show that there are approximately...
275,000 women, ages 50-64 in Florida who are under or uninsured. Slightly over 175,000 of these women reside in the 20 participating counties. Since late 1995, CDC grant funds have allowed the Program to provide screening services to slightly over 10,000 eligible women. Annually, the participating counties screen approximately 3,500 women or about 2 percent of the eligible population. One hundred thirty women have been diagnosed with breast or invasive cervical cancer through this Program in Florida. As you know, CDC funds cover reimbursement at the Medicare rate for breast and cervical screening services such as Pap smears and mammograms. There are also limited funds for specified diagnostic procedures 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 of treatment. Many others also donate services to the breast and cervical program. These include oncologists, radiologists, radiation oncologists, pathologists and hospitals.

The scenarios mentioned include the following:

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

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

- Another county program has seen a total of 10 women with cancer and they have two to three physician providers and one hospital provider who agrees to see each county program client. 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 program reviews 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 see one to two clients per year have formed three separate groups who have agreed to see one to two clients per group, for a total of three to six clients per year. This would not be sufficient coverage if the rate of diagnosing cancer continues.

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

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

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

Our providers are showing signs of abandoning this program unless we are able to provide them some assistance that is not available through the CDC grant.
Thank you for your personal interest in Florida's Program. If you have further questions, please feel free to contact me at (850) 487-2945, or Ms. Margo C. Blake, Program Manager for the Breast and Cervical Cancer Early Detection Program at (850) 488-2901. We look forward to a successful conclusion to this year's session and wish you our best.

Sincerely,

ROBERT G. BROOKS, M.D.
Secretary, Department of Health

cc: Mark Smith

Mr. BROWN. Second, just quote a couple of places, our providers, again Secretary of Department of Health in Florida to the Senator, 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. And also CDC has informally conveyed to us that they may award the Florida program more funds for breast and cervical cancer services in our next 5-year grant cycle, which begins this October. While this is positive news for many thousands of women who need these services, we also believe this will have a domino effect and the providers who provide incoming treatment. He goes on to—the director of—Secretary Brooks then goes on to sort of brag about the program and the good things it has done, but also to warn us that as we screen more people we are in a sense leaving more people hanging out to dry. And I would just like to enter that in the record and make that point, that treatment is every bit as important as the screening.

Thank you, Mr. Chairman.

Mr. BILIRAKIS. Mr.Lazio.

Mr. Lazio. Thank you, Mr. Chairman. First of all, I want to thank you for your work. And while I don't want to put you particularly on the defensive, I do want to ask some questions, because I am very concerned with the numbers being thrown around and the huge disconnect between the physicians and the providers on the ground that speak to me about the problem and the actual women who have delayed diagnosis or have been diagnosed and have not received treatment, and what you are saying—and I think we are going to hear from some of the witnesses who have on the ground experience with this—let me begin by just asking you about these surveys, the University of Michigan survey, for example.

How was that conducted, to the best of your knowledge? Were any women surveyed individually? Did we actually go—so you never talked to any women who actually were in the program.

And let me ask you this: So we don't really know in any real sense about the continuity of care. When you say, for example, that a treatment was "initiated," we don't know whether that was an appointment or whether it was surgery or radiation, chemotherapy, reconstruction, Tamoxifen. We have no idea what that means and whether it was spotty and sporadic or whether it was initiated.

There is a big difference between when someone makes an appointment and may have one opportunity to see a physician. Someone who gets the quality of care that we would want for our children, or for my mother, for example, you would want to have the peace of mind to know that they—those women who are testing positive are getting the continuity of care and the quality of care that will help them battle cancer and win the war as best they can.
Ms. Lee. As I stated in my testimony, we are not able to collect data on the type of treatment, or even more difficult, on the quality of treatment either from the perception of the providers or the perception of women. That is not something that we are able to do. We had defined “initiated treatment” to mean the treatment was initiated, not that an appointment was given. So that is how we have told the States when they provide us the data, don’t tell us that you gave them an appointment or gave them a referral. That is not good enough. We want to know that treatment was initiated. But after that point, our data systems do not allow us to further characterize the quality of the care.

Mr. Lazio. Isn’t that a problem? Don’t you see that as a problem?

Ms. Lee. Oh, yes, but I will put it to you to find out the quality of care of any woman in this country getting cancer treatment. The data systems are not there to tell us. It is a—

Mr. Lazio. But I guess my concern is, it is very difficult to have credibility in making—I am not challenging you on this right now personally to suggest that 92 percent of the women are getting care and of the remaining 8 percent, some are refusing care and it sort of creates the imagery that everybody is getting the kind of care that we would want for our children, and I say—because I know men get breast cancer, as well—men or women, whatever—when, in fact, we have no clue as to whether we have the standard of care that we should expect.

And so I pose that as sort of a conclusion for me, that I think that these numbers are—assuming that they are correct at all, and I don’t know; I have no basis as to whether they are correct or not—they certainly are very misleading, because all they are saying is, first of all, they are not even speaking to the women, which seems to me a very significant flaw to begin with, and then you are not surveying the continuity of the care or the quality of the care.

One would think CDC would embrace with open arms a system that is reliable, whether there are quality standards by way of the Medicaid system, at both the State and Federal level, that you would want to have a system where women could be better educated where treatment was available in a reliable way, that it is easier to market and get the word out.

I am puzzled by the position of CDC, if I can call it a “position” right now.

Mr. Bilirakis. A brief response to that. Don’t forget, we will have a second round of questions.

Ms. Lee. The information on the percent that receive treatment, that is from the woman; each time a woman is screened in our program, we receive information on all subsequent outcomes through the diagnosis and initiation of treatment. The telestudy, the study I alluded to, were interviews with providers of care; and so that is not with the woman, you are correct. But we believe and we have had lots—I mean, you just have to believe what the States tell us. We believe, the data system that we have, about the 92 percent. We think it is a very good data system.

Mr. Lazio. There is obviously a disconnect, though, between what the States—if you believe between what the States may be telling you and what is happening on the ground—and we didn’t get into this, but I am wondering what type of quality assurance
you have that the States are actually providing reliable numbers on top of that.

Mr. BILIRAKIS. We will do that in the second round.

Ms. Eshoo.

Ms. ESHOO. Thank you, Mr. Chairman. And thank you, Dr. Lee, for not only being here today and testifying, being part of this hearing, but for the work that you do at CDC.

I want to pick up where Congressman Lazio just left off and present this question to you. Why is there such a disconnect between the numbers that you are giving us and the cases, the women that come to us in our districts and say, I couldn’t get treatment?

Can you describe the treatment that has been described to you by the States? My experience in tracking my own constituents—because I ask good questions of them: Tell me what you did. Where did you go? Where did you get the money from? Who helped you? What doctor did you go to? What clinic did you go to? What hospital did you go to? Who told you about it? What community organization helped you?

It is, at best, such a bumpy patchwork quilt.

Yes, there are extraordinary people out there that are willing to help people, but I don’t think that is the question. I think the issue is that there be a smooth transition between detection and treatment and the coverage for that treatment. So tell me your stories.

I know what mine are. I would rather have you tell the stories, not so much in terms of the statistics that you have just given us, but some of the specifics of how you have tracked them and what the stories are of how there is a smooth transition for this 90-something percent of the 12 to 15 percent. Of course, you know, in terms of screening, maybe you don’t have enough money to get to the 100 percent, but that is really not what this hearing is about. The hearing is on the bill and how the approach that we are taking in the bill which—I understand there is some discomfort, but, boy, am I uncomfortable about what I just described.

So can you tell me your story?

Ms. Lee. Sure.

In the first—our statistic, I think maybe is sometimes overinterpreted. All it says is that 92 percent of women initiated treatment.

Ms. ESHOO. Dr. Lee, have you gone out on the road? Do you know what this 92 represents?

Ms. Lee. That is just initiated; it doesn’t even mean they completed the first round. It just means treatment, and breast cancer treatment is a very prolonged affair, so all that says—so don’t overinterpret that statistic. And it is very, very difficult when you are dealing with 2 million records to get much more detail on treatment than that.

Ms. Eshoo. I think when we hear the word “treatment,” we make the supposition that this is beginning, middle, and end when we are treated for something. I mean, I think all of our instincts tell us to believe that.

Ms. Lee. So all our data suggests, all that 92 percent suggests is that they initiated treatment, which is a multistep—

Ms. Eshoo. Do we have any idea how many concluded treatment?
Ms. Lee. No. And for both of those cancers, the treatment may be ongoing for several years, so it is a very difficult thing to collect lots of information on.

Let me say two other points. The first is that as a physician and as the director of this program, I cannot tell you how important I think it is that all of these women who are diagnosed with cancer get what they need in a timely and appropriate fashion and in a smooth way. I can't tell you.

I mean, I have been taking care of patients with breast cancer for many years, not many anymore because I am full-time at CDC, but I do some. So it is very important, and it is something that we are very committed to; and it is difficult in the situation in which we exist, but we do what we can——

Ms. Eshoo. What——

Ms. Lee. Just a minute. To say that——

Ms. Eshoo. You're out of time.

Ms. Lee. You asked me a big question, and you want me to tell you a story.

To say that our report says it is smooth is not what I think our report says. I think our report, the report from the seven-State study actually details a laborious, bumpy, fragile process; and I would not characterize the process that we know that is going on out there as "smooth" for women.

Ms. Eshoo. Can you define for us what "initiate treatment" means? Does it mean a woman making an appointment with a doctor? What does it mean?

Ms. Lee. I addressed that earlier. That is not what it means.

Ms. Eshoo. I had to step out.

Ms. Lee. It means that she initiated treatment, and for breast cancer, that usually means and when we—we have some data from a three-State study that is preliminary, that that is almost always surgical; and for cervical cancer, that would usually be surgical, sometimes it is radiation.

What we require of the people giving us the data is, it is not an appointment, it is not a referral; it is that it occurred, the first step of which for both of those cancers is only the first step.

Mr. Bilirakis. The gentlelady's time has expired.

Again, I repeat, we are planning to go through a second round for those who haven't already heard it.

Mr. Bryant.

Mr. Bryant. Thank you, Mr. Chairman. Thank you, Dr. Lee.

I have a lot of questions and will try to squeeze them in the first round. Keep your answers as short as you can.

Ms. Lee. Not necessarily my strength, but I will try.

Mr. Bryant. Does it go without saying that all the States and territories and tribes participate in this program?

Ms. Lee. Yes. 50 and 5 and 15.

Mr. Bryant. There are no gaps there?

Ms. Lee. There are some. Not all territories are participating and many tribes are not participating.

Mr. Bryant. So there are gaps that are not covered under current legislation?

Ms. Lee. Yes.
Mr. BRYANT. Second, in terms of a situation, have you run across evidence where people don't go to a screening because they know they don't have the ability to pay for treatment? Do you think that is a possibility?

Ms. LEE. Right. Anecdotally, again from our study in the seven States, the providers who were interviewed told us those stories, that there were women that didn't want to get screened because they knew—didn't know what they would do if something was wrong.

Mr. BRYANT. In your statement, you mentioned that the current method is an ad hoc patchwork of providers, volunteers and local programs. Or maybe it has been stated. I am not sure you stated that, but it has been stated that, and that often results in treatment that may be unpredictable, delayed or incomplete. Would you characterize this as substandard treatment in some cases?

Ms. LEE. In my professional opinion as a physician, if it is—certainly, if it is incomplete, that is substandard; and I myself would not want to have to feel anxious about where I was going to get my next medical oncology visit.

Mr. BRYANT. Would there be in the care, CDC screening care, as a result of CDC screening, if it were Medicare, would there be the resources there? Would there be problems in finding Medicare treatment, as many problems?

Ms. LEE. Medicare?

Mr. BRYANT. Medicaid, I am sorry.

Ms. LEE. I am not an expert. You know, Medicaid is administered in each State differently, and some States have a much stronger Medicaid program than others, I am told. But Medicaid is a form of insurance. These women we treat are uninsured, and I would assume if you have insurance, you are going to do better. I am not an expert in this.

Mr. BRYANT. Let me ask you, I guess, the big question that I have. Realizing your role in the CDC and you are actually—CDC is actually implementing the law that Congress passed in 1990 in terms of what you can do and what you can't do, but you cannot provide treatment directly?

Ms. LEE. We cannot provide funds for treatment.

Mr. BRYANT. There is a process in place by this law that says you have to go out and find it where you can. The State has to do that. Is there a better way, and in your position, can you talk about this? Can you say if there is a better way, how Ms. Eshoo's and Mr. Lazio's bill is?

Ms. LEE. I am not at all—I am a physician, a scientist and a public health professional. I am not an expert on health care, how one finances health care, and on policy and legislative issues, so I don't think I am a good person to give you an opinion on that.

Mr. BRYANT. Is this—from an expense standpoint, we have a budget up here and we have to deal with that. I have figures from Tennessee, and it shows that in the year and a half that apparently Tennessee has been recording, we have had something like 1,161 procedures, 335 mammograms and 826 Pap smears; and with the good, able assistance of Dr. Coburn, he has given me dollars, charges on average, and if you divide the number of these tests into the amount of money you received in Tennessee, which was
over a million dollars for funding that Tennessee received, that is fairly expensive. That is almost—not quite $1,000 a procedure, but it is getting up there.

Now, is that money really—

Ms. Lee. You mean, per screening test?

Mr. Bryant. On average, per procedure. Is that—it doesn’t cost that much to do a Pap smear or a mammogram?

Ms. Lee. No.

Mr. Bryant. Where is the money going?

Ms. Lee. We estimate about—on average, and this is back-of-the-envelope stuff, when we kind of try to figure out—but it is $100 to $150 per person, which factors in—which factors in the subsequent diagnostic tests, et cetera.

Mr. Bryant. Where does the other money go then?

Ms. Lee. There are startup costs. There is—40 percent goes to pay for outreach, professional education, quality assurance, public education, and administrative costs. So not all of the money goes to that.

It is also—this is a complicated program. States are not—most States have not been in the business of providing screening services to older women, and so there is usually a 12-to-24-month lag time in their ability to really get out and implement this program.

Mr. Bryant. Thank you.

Mr. Bilirakis. Mr. Waxman to inquire.

Ms. Capps to inquire.

Ms. Capps. Thank you, Mr. Chairman, and I am grateful to you, Dr. Lee, for your testimony today and appreciate that you are here. I want to make sure I have the ground rules that you have been charged with at CDC in doing the screening, making sure that States are responsible if they sign up for the screening procedures to follow up with treatment.

You do not do treatment of even precancerous lesions?

Ms. Lee. Correct, with the Federal funds.

Ms. Capps. With Federal funds?

Ms. Lee. Correct.

Ms. Capps. So it is up to the States to catch what happens after the screening on behalf of the individuals?

Ms. Lee. We require them to ensure that that occurs.

Ms. Capps. I am very mindful that we have in the audience people with their own personal stories and you are now on the stand and they are going to be presenting their testimonies, but they won’t have a chance to ask you.

So I want to try—please forgive me—to put myself in a position of being a woman in one—in California who is scared to death because I have a lump, or I have some symptoms, and I am aware that this screening program exists; and so hesitantly I go, but I have no health insurance. I don’t qualify for Medicaid in my State. I work, but like many women, I have no benefits that include health insurance. So I am terrified.

Now, I go for the screening and I get the terrible news that I have a problem that needs to be addressed. What then? What happens in terms of your protocols?

Ms. Lee. Our program is, we may pay. We are able to pay for the diagnostic procedures that you need. So, for example, if you
had a breast lump, one might need a diagnostic mammogram, a fine needle aspiration and ultimately a breast biopsy.

Ms. CAPPS. That is still the screening?

Ms. LEE. Yes. And we can pay for a surgical consultation. All of those services can be paid for with Federal funds, and the breast biopsy.

Mrs. CAPPS. That is still the screening?

Ms. LEE. It is now the diagnostic follow-up portion.

Ms. CAPPS. You would find my doctor for me to go get that?

Ms. LEE. Yes. And we can pay for a surgical consultation. All of those services can be paid for with Federal funds, and the breast biopsy.

You are in California. You are lucky. California has a $12.9 million—I don't know exactly what you would call it from the conversion of Blue Cross-Blue Shield from nonprofit to profit.

Mrs. CAPPS. Put me in another State where there isn't this.

Ms. LEE. In California, they have been able to use that to pay for treatment.

Ms. CAPPS. Right, but some States don't have that.

Ms. LEE. Correct.

Ms. CAPPS. So then what do I do? I am in this doctor's office and they say it is worse than you think.

Ms. LEE. It is really cancer?

Ms. CAPPS. It is really cancer.

Ms. LEE. Depending on the State that you are in—and this is what the materials that we have given you discuss—there are many, many strategies. The States have case managers to help you with this, and what they can do is they can see if you are really eligible to apply for Medicare. Some women are and have not done it.

Ms. CAPPS. For someone to help me do this?

Ms. LEE. Yes.

Ms. CAPPS. Who is that person?

Ms. LEE. Sometimes at the local level, sometimes at the State. We call them "case managers" for want of another term; and as you are aware, I think, through this committee, we were given authorization to do that. And we have extra money in fiscal year 1999, as I mentioned earlier, that we are putting toward augmenting this already-existing service. So there are people, case managers, to help you with this, so they can—they have also in some States, or in most States, I think they require the screening providers to set up networks with treatment providers who are different, as you know, to provide in-kind reduced-fee free.

People might be sent to charity hospitals. A number of counties have county indigent funds. In States where this is available, they are able to draw down on that. There are private foundations who have provided funds. Some States have tobacco tax money. So there are a variety of strategies which are outlined in the materials we have provided.

Ms. CAPPS. I guess this is piecemeal.

Ms. LEE. It is very piecemeal and fragile.

Ms. CAPPS. Is there a time limit? I don't know very many cancers that are treated in one fell swoop. This could be a year-long process for this woman?

Ms. LEE. Right. I think what we have encouraged our States to do is to insure the first course of treatment.

Ms. CAPPS. "First course" meaning how many?

Ms. LEE. Meaning the first course.
Ms. Capps. I think the picture is there. Some have questioned why a woman would not avail herself of this screening process knowing on the street what is in store. I can understand the terror.

Mr. Bilirakis. Dr. Coburn.

Mr. Coburn. Thank you. I would just comment to Ms. Capps, having practiced for 16 years, many women won't get screened, even when they have insurance, if they have a lump, because of the tremendous fear of the unknown; and I would put forth to you that that is the majority. Although there are some in terms of what you have raised, the majority of women who find a lump have such fear that they are intimidated from going to be screened or treated. And that is what we need to address. We need to address that issue with the women of this country, and the CDC should be doing that through public television ads and things like that. That is a good way—

Ms. Capps. If I could just mention, a large part of the fear is not knowing who is going to be there for you all the way through.

Mr. Coburn. Well, Dr. Lee, I want you to bear with me. I intend no personal animosity toward you, but I have a lot of animosity toward the CDC.

The name of the CDC is Centers for Disease Control and Prevention. You just said a minute ago that your goal was to find precancer. But the CDC's goal is to prevent, and I just—I want to go through—just for the record, if you would answer yes or no for me a couple of these questions.

Do we know the causative agent for cervical cancer?

Ms. Lee. I think we know at least the major causative agent.

Mr. Coburn. For 94 percent of it. And what is that?

Ms. Lee. My understanding—I am no expert in this particular part, but my understanding it is human papilloma virus.

Mr. Coburn. That is correct. Do we also know that if we did not have human papilloma virus, that we would cut that by 94 percent?

Ms. Lee. I can't tell you how much we would cut it, but it would be cut substantial—cut probably close to zero.

Mr. Coburn. The scientific studies say there would be no cervical cancer, in essence, if there wasn't human papilloma virus. And is it not true that human papilloma virus is transmitted intrapartumly, in other words, at delivery to neonates?

Ms. Lee. This is—as I said, HPV is handled in a totally different part of CDC.

Mr. Coburn. I understand, but you have a cancer prevention and screening program; and what I am asking you is, is that not true?

Ms. Lee. I do not know the answer.

Mr. Coburn. The answer to that is true. There are six studies now that confirm that a child in utero can be infected by their mother from human papilloma virus, which means many of our young women today will never be exposed to human papilloma virus through intercourse, but can still get cervical cancer.

So my question to you is, why is the CDC—and I have asked you this question before—not making human papilloma virus a priority both in terms of prevention, reporting, and public education about this disease?
Ms. Lee. As I said earlier, our program is about administering the Cancer Mortality Reduction Act, which is providing screening services. I have no——

Mr. Coburn. Pardon me, Dr. Lee. There is nothing in the act that says that you can't use that money to prevent the disease. We are talking about reducing mortality, reducing disease; and my question to you is, why is some of the $150 million a year not used to educate the American public to reduce this disease?

There are 4 million new cases a year of human papilloma virus. If the women in this country knew the poor job that CDC was doing on human papilloma virus and, if they dare, did it on breast cancer, I dare say that most of the people that work for CDC in those areas would be hung. The fact is, we have an epidemic of a disease causing cervical cancer and nothing this government is doing is working to prevent it.

I agree, I think you are doing a good job in terms of trying to identify it. I am concerned that you are not funded adequately, and I know that you might find that amazing for me, but if there really are 11 million women out there that can't get a Pap smear at a health department and can't get breast screening over 40 and there are 11 million, $150 million is not enough to initiate a program for that.

I am also concerned that over $60 million a year isn't going for screening; that it is going for overhead. I just happen to have the data CDC gave me. The total CDC cost per screen is $400 per screen. I tell you, that is way too much. We can screen twice as many people with what it—we should be able to screen twice as many people, based on what you are spending.

In Oklahoma, it is $550 per person. In Tennessee, it is $1,000 per screening event. That is too expensive. There is too much overhead and not enough efficiency in the program, and my question is, what are you doing to make sure we give more screenings with less overhead spent on it?

Ms. Lee. The overhead, by law, is limited to 10 percent. It is not all that you said; the overhead, by law, is limited to 10 percent. And many States don't even reach that 10 percent.

Much of what we are talking about in that 40 percent that I mentioned earlier is public education, which includes the States' own materials on the risk factors for breast and cervical cancer. So there are women in this program hearing about HPV. We, as a division, don't provide those materials; the States have them. But it is outreach. It is professional education. It is quality assurance. That is the bulk of the moneys that doesn't go to pay for screening services.

Mr. Coburn. If I could have unanimous consent to insert what was sent to me by fax from the CDC office here, of those records.

Mr. Bilirakis. Without objection.

[The material is retained in subcommittee files:]

Mr. Bilirakis. Mr. Waxman.

Mr. Waxman. Thank you, Mr. Chairman. I want to look at the insert in the record, and I would hope we could get a statement from CDC about what more can be done to prevent cervical cancer. I presume if it is through intercourse, protection through inter-
course might prevent transmission; but if it is through birth transmission, I am not sure—

[The following was received for the record:]  

Cervical cancer is nearly 100 percent preventable, yet according to the American Cancer Society, an estimated 12,800 new cases of invasive cervical cancer will be diagnosed in 1999 with about 4,800 women dying of the disease. The cervical cancer death rate declined 45 percent between the periods 1972-74 and 1992-94 and the overall incidence of the disease has decreased steadily from 14.2 per 100,000 in 1973 to 7.4 per 100,000 in 1995. This is largely attributed to the effectiveness of Pap smear screening for cervical cytology. Studies that have identified risk factors associated with cervical cancer have shown that cervical cancer is closely linked to sexual behaviors, human papillomavirus (or HPV) infection, immunosuppressive disorders such as HIV/AIDS, as well as a failure to receive regular Pap smear screening.

Experts agree that infection with certain strains of the HPV is one of the strongest risk factors for cervical cancer. Other than abstinence from sex, means of protection from HPV are uncertain. The protection provided by condoms has been difficult to evaluate because current laboratory tests for HPV infection cannot determine whether an infection is new or acquired in months or even years before. Microbicides under development may provide some protective benefits. The most promising approach for prevention of transmission will be the development of preventive vaccines. Carefully designed studies of all of these prevention approaches to HPV will be important in designing more effective prevention strategies for this infection.

Currently, the most important risk factor for developing cervical cancer, at least from the point of view of what we can do about it, is the failure to receive regular screening with a Pap smear. Since its introduction 50 years ago, the Pap smear has been widely used and is credited with the steady decline in cervical cancer deaths in the United States. Nationwide estimates from 1994 indicated that well over 90 percent of all U.S. women had received a Pap test at least once in their lives and that 80 percent had obtained one within the preceding 3 years.

In fiscal year 1999, with Congressional appropriations of $159 million, the CDC entered into the ninth year of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). The NBCCEDP has provided more than 1.1 million Pap tests to a total of more than 700,000 women. Almost half of the women screened are from minority racial and ethnic groups. Of Pap tests provided, about 3 percent were abnormal; more than 31,000 cases of precancerous lesions were ultimately diagnosed, and 508 women were diagnosed with invasive cervical cancer. These statistics illustrate a key point for this essential public health program. The main purpose of cervical cancer screening is to find precancerous lesions, treat them, and cure them, so that these women do not go on to be diagnosed with cervical cancer. The program has potentially averted cancer in more than 31,000 women. Treatment of precancerous lesions is also generally less complicated and less expensive than treatment of cervical cancer. Of all the women diagnosed with cervical disease through our program, fewer than 2 percent actually had a diagnosis of cancer. This underscores the success of Pap testing and emphasizes the proven strategy that we as public health practitioners can use to fight this cancer.

With existing resources, the national program is able to screen 12-15 percent of the eligible population annually. There are an estimated 11 million women eligible for this program who are not receiving screening services due to lack of resources.

Mr. Coburn. Would the gentleman yield for just a moment.

Mr. Waxman. Sure.

Mr. Coburn. I would be happy to yield some time back. The studies now show that condoms are ineffective in preventing transmission of human papilloma virus. There is no prevention we can give for human papilloma virus.

Mr. Waxman. I want to know more about that subject, but I don't want to use my 5 minutes on that area right now. The job you have is to work with a screening law for breast and cervical cancer, so that we can find those cases that do exist and hope to prevent diseases; if you can find cancer early enough, treatment can be a cure or at least a containment of this disease.
In order for it to be a containment or a cure of the disease, people have to get some treatment. And under the law, States are supposed to be creative in trying to find charity care or some other place where women can get treated for breast or cervical cancer.

In 1988, the study you did points out that treatment is a major issue for these programs and they have responded creatively, but States are concerned about the lack of treatment resources and the findings say it is very labor intensive to find treatment. Finding treatment services diverts resources away from the program, and the lack of treatment services negatively affects the recruitment and restricts the number of women to be screened.

Can you talk about that fact, those numbers? It sounds to me like we are putting resources into trying to find treatment that could be used for screening more women.

Ms. Lee. That is what that study of seven States said. Remember, those were extensive interviews with many providers and programmed people in the seven States. And that is what they felt. We have not quantified that amount that is diverted from—well, it is really diverted from reaching out and getting women to be screened into these other efforts. We have not quantified that, but we know that it happens.

Mr. Waxman. This committee has looked at the changing nature of health care delivery, and more and more people are in managed care. There are studies, I think one was recently reported in the Journal of the American Medical Association, that there is less and less charity care being provided by providers who are part of managed care plans.

Do you think that has impacted the ability to get services for women who are screened?

Ms. Lee. That was definitely one of the findings of the study, that these providers and the State health department personnel told us that with the changing in the health care systems that are out there, fewer and fewer providers felt that they were able to have control, have autonomy over the decision whether, when and how much charity or reduced-fee care they could provide.

So that is definitely something that we found in our study.

Mr. Waxman. The chairman asked you questions about how successful the program is in finding treatment, and I think you indicated that it is reasonably successful in finding treatment for those who are screened. But the fact of the matter is, I think your statistic was that only 15 percent of eligible women are ever screened.

Ms. Lee. Those are our estimates, yes.

Mr. Waxman. Maybe it is because they don't want to know, as Dr. Coburn suggested, because of fear. Maybe it is because they don't have assurance that there is going to be treatment available to them because they are relying on hope for charity care. Maybe it is because a lot of resources that could be used for screening are being diverted to trying to call up all the various resources to see if care will be available for women who are screened.

Are those three factors important in the fact that we see such a low rate of women being screened?

Ms. Lee. No. I think the main factor is, the level of our current resources we have to give out to the States doesn't allow any more women to get screened.
Mr. WAXMAN. Isn't that—maybe my question wasn't clear. You give out money to the States to screen women, but a lot of that money has to be used to look for treatment for those who are screened. So therefore——

MS. LEE. No, I think the majority of money we put out to the States is used for screening services.

Mr. WAXMAN. A majority.

MS. LEE. Sixty percent must be.

Mr. WAXMAN. That means 40 percent is being used for some other purpose?

MS. LEE. Correct.

Mr. WAXMAN. If more than 60 percent was being used for screening, wouldn't you have a higher figure screened than 15 percent of eligible women?

MS. LEE. Except one couldn't administer this program which is a comprehensive approach with all the money being paid for screening. We know that——

Mr. WAXMAN. Because you have to find treatment for them?

MS. LEE. No, because we need to do public education, professional education, quality assurance, partnership development. There is a whole—we have to figure out ways to go out and bring women in for screening.

Mr. WAXMAN. What percentage of the money is being used to seek out treatment?

MS. LEE. We have never quantified that. I can tell you that the additional funds that we have allocated for case management beginning in fiscal year 1999 will augment some case management funds that are there, and there are about 5 percent.

Mr. WAXMAN. Just to conclude my time, and I appreciate the chairman's being tolerant, your own report said that it is labor intensive to find treatment and finding treatment services diverts resources away from the program.

MS. LEE. That is true. We have not quantified what proportion—how much that is, though.

Mr. WAXMAN. And you also concluded the lack of treatment services negatively affects the recruitment and restricts the number of women screened.

MS. LEE. True.

Mr. WAXMAN. So what are we arguing about?

MS. LEE. What is the most important reason.

Mr. BILIRAKIS. Let us continue the argument in the second round.

Dr. Ganske.

Mr. GANSKE. Thanks, Mr. Chairman.

You know, I think a lot of us have been concerned about the uninsured, the 40-something million who are uninsured. And it seems to me that the testimony we have had today is another example of some of the reasons why in the larger population we have that many uninsured, too, and that is what I have heard is that a large number of women who would qualify for this program for the screening simply haven't heard about it. Is that right?

MS. LEE. I don’t know the answer. We haven’t—we haven’t assessed that.
Mr. GANSKE. Did I not hear something to the effect that only 15 percent of those who are eligible take advantage of the program?

Ms. LEE. Correct. That is because we can’t—we don’t have the funds to give the States any more.

Mr. GANSKE. Is it that, or is it that, you know, women who might take advantage of it haven’t heard about the program? There are language problems? There are problems with transportation? There are problems with getting to the offices?

Ms. LEE. All of those—those are all true and we—those are all barriers, and we believe those are important factors; but also true is that we can only give States $1 to $5 million a year to do this program, and in big States that doesn’t even cover—it covers a very small proportion.

Mr. GANSKE. What are the income and resource eligibility requirements?

Ms. LEE. They vary by State, but the CDC has capped it at 250 percent of poverty or lower. Some States have much more strict requirements, so some States, it is at 250 percent of poverty. We also—these women must be uninsured or underinsured, so if they have Medicaid that can pay for a mammogram or Medicare that can pay for a mammogram, then they are not eligible for our program.

Mr. LAZIO. Would the gentleman yield for just a point?

Mr. GANSKE. Sure.

Mr. LAZIO. I have the statistics in the back, unless my statistics are wrong. The lowest percentage in terms of threshold that a State has is 150 percent. There are none below 150 percent, but that is what I have, at least, in black and white in front of me.

Ms. LEE. We can get that for the record.

[The following was received for the record:] There are no State programs using an income eligibility criteria below 150%.

Mr. GANSKE. As I have looked at the total uninsured problem, about 25 percent of the uninsured are children. About half of those qualify—would qualify for Medicaid or CHIP, but they aren’t enrolled, and for many of the same reasons, the barriers we just talked about. So it would seem to me there should be some strategies in addition to the funding that we would need to look at in order to address this problem.

Now, maybe Mr. Lazio can help me on this, because I am a co-sponsor of this bill, as is, I think, nearly everyone on the Commerce Committee, but the CBO’s preliminary cost estimates of the Senate companion bill, I think is $315 million over 5 years. Is that in the ball park?

Mr. LAZIO. First of all, it is a preliminary estimate in the Senate bill, and it is not—this bill has not been fully scored by CBO. And I can only tell you, if you—I can provide you the amount of women that are being diagnosed right now, which I can give on a State-by-State basis; but visually, you can take a look at it, and I can provide it to you later on, and you can make some judgment as to where you think the real cost is going to be.

Mr. GANSKE. So, at a minimum, we may be looking at doubling or tripling then the appropriations in order to make available treatment in addition to just diagnostic screening?
Mr. Lazio. Well, first of all, you know, I don’t think we have any basis for that until they issue some final numbers. I think that there is an anomaly between even the preliminary number, and if you look at the number of diagnoses that are occurring, how they get there, but we haven’t had a chance to review that?

Mr. Ganske. I would just ask Dr. Lee, having a rough idea of the expense ratios for diagnosis versus treatment, would that be in the ball park?

Ms. Lee. That is not something that I have any expertise in. Sorry.

Mr. Coburn. Would the gentleman yield?

Mr. Ganske. I would be happy to yield.

Mr. Coburn. One of the things that concerns me is that we have 11 million women identified who are not being screened. And one of the things we ought to think about doing is making sure we up the dollars for the program and hold it accountable to do that in an efficient manner, so that even though we are going to have treatment, we ought to find those women who need it, because right now the vast majority are not being found. One percent positive screening I believe is far less than the national average; is that not correct?

Ms. Lee. My read of the literature—

Mr. Coburn. On cervical?

Ms. Lee. No, because cervical cancer is very rare. It is more common—

Mr. Coburn. Your testimony was precancer.

Ms. Lee. No, it is higher.

Mr. Coburn. I would submit to the gentleman from Iowa, probably we ought to be increasing the program for this program as well as funding this bill.

Mr. Bilirakis. The gentleman’s time has expired.

Mr. Green. Thank you, Mr. Chairman. Dr. Lee, I think you obviously hit a deep pocket of concern by a lot of committee members. Again, most of us, I know, are cosponsors of the bill.

One of the concerns I have—and I have some testimony here from a lady who is not scheduled to testify, Josefina Mondada, and her experience—Mr. Chairman, I would like to put her testimony into the record.

Again, she is not—she is not on the witness list, but she was diagnosed, and she is in a rural part of Texas. I see Yancey, Texas. Of course, I am from Houston, and Yancey—I don’t know where it is, but it is an hour from San Antonio. And she was actually working in a hospital. Her husband is disabled. She has $26,000 in bills, and their income—because her diagnosis and her treatment is only $1,100 a month. What concerns me is that in your testimony you talk about—

Mr. Bilirakis. Is the gentleman asking to have that be made part of the record?

Mr. Green. I will submit her testimony as part of the record, Mr. Chairman.

Mr. Bilirakis. Without objection.

[The information referred to follows:]
PREPARED STATEMENT OF JOSEFINA MONDADA

Good Morning. My name is Josefina Mondada and I am from Yancey, Texas. I was diagnosed with breast cancer in September 1998. I was working as a nurses' aide at night so I could care for my husband during the day who had a stroke in 1992 and suffers from diabetes. I did not have any health insurance when I discovered a lump. I was terrified and called my daughter who made arrangements for me to get a mammogram through the screening program where I live.

The woman who helped me at the clinic asked how I would take the news if I had breast cancer and I told her I would take it as it comes. What I didn't realize was that as I fought breast cancer I would face so many obstacles to getting treatment and getting that treatment paid.

A week after my mammogram I got the bad news. I was told I needed treatment. My case worker recommended that I get my treatment in either San Antonio, about an hour from my house or in Galveston, about 5 hours away. My caseworker did recommend that I not go to the doctor in town. I made a decision to try and get my care as close to home as possible. I first tried to get treated in San Antonio because it would be close enough to my home that I would be better able to care for my husband. Unfortunately I was told I did not qualify for services in San Antonio because they did not provide services to anyone who did not live in that county.

I decided to go to the local doctor despite my case worker's concerns. I just could not leave my husband for the extra time I would need to go to Galveston. After my surgery, I developed an infection. I went in to see my doctor and 3 or 4 days later he told me I needed to go back in for another surgery—that there was more cancer that they didn't find the first time.

It was then that the bills from the doctors started to pour in. Luckily the hospital only asked me to pay 20%, but I have received bills for all my other treatment, including the two surgeries, the chemotherapy, radiation, pathology. At this point I have accumulated more than $26,000 in bills I am unable to pay.

I tried to get Medicaid but was turned down—there is still no coverage. What if I have to go back into the hospital or have any more treatment? What then? I don't know what I will do?

Our income—$704 from social security disability and $297 from my husband's retirement—doesn't cover our expense now that I am unable to work. What isn't spent on essentials goes to control my husband's diabetes. The doctor won't allow me to work and I am afraid that I am too weak to take care of the patients in the nursing home where I worked.

Mr. Chairman, members of the Committee, I feel lucky I got treated, but that is only one part of the story. I worry every day about how to pay these bills. I simply don't have the money.

I don't want to be a burden to my family or my children. I really can't bear that. But what was my choice? Not to find out whether I had breast cancer? Not to get treated?

Thank you.

Mr. Green. Ninety-two percent of the women diagnosed with breast cancer and invasive cervical cancer initiated treatment. I know from experience in my own district in Houston, and hers is not too much different, that she now has $26,000 worth of bills. She has no insurance and even as a hospital employee, they only required her to pay 20 percent for her—for the hospital costs, but she had this other cost.

And that 92 percent included—would include someone like Ms. Mondada?

Ms. Lee. I am not sure. If she initiated treatment, it would be in there. That is all that that statistic discusses.

Mr. Green. One of the other questions I have, and I know in later testimony from Ms. Braun that she talks about the quality of treatment they receive should be the highest possible, and I know in my own office in Houston, oftentimes we get calls from constituents who—women who have managed care plans, and they question the quality of the treatment they are receiving. Of course, in Houston, Texas, we have M.D. Anderson as a State hospital, and
it is a facility—in fact, it is a self-referral facility; you can self-refer yourself without your local doctor, but it is a long way from home. 

Do you know—again, 92 percent receive some type of treatment, but there is no information on the quality of the treatment.

Ms. Lee. Correct, and that is very difficult to come by for anybody in this country trying to decide that.

Mr. Green. Let me ask—and again, being from Texas, and I know when I was in the legislature, there are a lot of Medicaid programs that States do not take advantage of because, again, to raise the State funding for it, they will just let it go back.

How many States do you think would participate in a program like this bill would call for?

Ms. Lee. I have no idea.

Mr. Green. Again, the frustration I remember as a State legislator, there were a number of Medicaid programs we could have provided, a very small percentage, and the States make that decision not to do it.

Obviously, the residents of those States are the ones losing it, but except for the recent history in the State of Texas, we had a surplus, but in the past we had deficits. And so even making this bill available, what this bill calls for, I am concerned that some States won’t even take advantage of it for that.

Mr. Chairman, I will yield back my time, but those are some of the concerns I have.

Mr. Bilirakis. I thank the gentleman.

Mr. Barrett.

Mr. Barrett. Thank you, Mr. Chairman.

It is unclear to me from your statements as to whether you oversee the entire program or simply the breast detection part of the program.

Ms. Lee. No, it is both the breast and cervical. They are of a piece, and our hope is that for women for whom it is appropriate, that women receive both screening tests through the program if they need it.

Mr. Barrett. And from the questions that Mr. Coburn had and his frustration with the cervical portion, is there another individual who has greater information in what is being done there?

Ms. Lee. Absolutely. The division of STDs—they have a long name, but it is basically the STD division, the Sexually Transmitted Disease division, is another part of CDC, another center; and they have the responsibility for human papilloma virus prevention of STDs.

Mr. Barrett. So none of the money from this program, though, is spun off into that program?

Ms. Lee. No, but we are cooperating on a demonstration project which we hope—we have already developed with them a demonstration project protocol, and we are hoping next year to do a program through STD clinics to see if STD clinics are a good place to screen women for cervical cancer.
Mr. Barrett. Maybe that ties into my next question, because it would seem to me that your target group is going to be different for breast cancer and cervical cancer.

Ms. Lee. To a certain extent it is.

Mr. Barrett. Your program, because of resources, is geared more toward postmenopausal women, so again I am assuming that that is not the same target group that you are going to be going after.

Ms. Lee. We provide screening services for cervical cancer, for Pap smear screening services for young women as well, and so if you want to know our target population for women for Pap screening are women who are sexually active or 18 years or older.

For breast cancer screening, our target starts at age 40, and then we end pretty much at 65 because those women are covered by Medicare. We encourage even the cervical cancer screening program to reach out to older women because Pap screening is available through other Federal programs to younger women through Title V, Title X, et cetera. So there are other Federal moneys available to screen young women with Pap smears, but we screen women of all ages for Pap smears.

Mr. Barrett. Again, for this program, your target audience is the older women?

Ms. Lee. Generally, but then we also screen younger women with Pap smears, but they are not our target.

Mr. Barrett. The actual screening, where is it done?

Ms. Lee. You name it. It is all over. States set this up; it varies in States. It can be in health departments, private physicians’ offices, hospital clinics, migratory health clinics, YWCAs, all kinds of places.

Mr. Barrett. So you send the money to the State?

Ms. Lee. We send the money to the States, and the States, depending on how it best works for them in their State, they contract with different—subcontract with different providers in their States; and the providers can be many, many different forms.

Mr. Barrett. The outreach is also contracted with the State?

Ms. Lee. We give the money to the States through a cooperative agreement mechanism, and the States do all of the real work; and we provide oversight and technical assistance and guidance.

Mr. Barrett. Okay. For the outreach for the cervical cancer, what type of outreach is generally done?

Ms. Lee. Again, it is all kinds of things. And this would be for breast as well. We are trying to—we are targeting the high-risk women and the women who are otherwise not getting screened, and we know that minority women and older women fall into those categories. So we go to all different places. We go to churches, to beauty salons, to migrant health centers, to—there are all kinds of networks that States and local—

Mr. Barrett. When you say “we,” you don’t mean CDC?

Ms. Lee. The program does, which really means the States and their contracted providers.

Mr. Barrett. The concern that I have in a way echoes some of the questions that Mr. Coburn had, and that is how best to deal with the HPV problem, because it does appear that if you can deal with that early on, you are going to have a high degree of success.
And I would offer, Mr. Coburn, if we think we need to put more money in that program, I am more than happy to work with you to put more money in that program because the numbers are pretty amazing. And maybe if we haven’t done so already, we can have someone up here to talk about that specific program.

What do you think we should be doing for that specifically? If we can cure this disease by catching it, what should we be doing?

Ms. Lee. Well, it is very, very important and all kinds of studies indicate that an important risk factor on cervical cancer is not being screened. So we are providing that, because if we screen it and catch the precancerous lesion before it turns into cancer and treat it, then they are not going to get cervical cancer. That is one important thing.

I am not an expert, but I know the National Cancer Institute is supporting research on vaccines for HPV, and it is promising. They are certainly in the research phase, but if you can give people a vaccine to prevent acquiring serious HPV, then that would be good, too.

Mr. Barrett. I would just assume very quickly, if I could, Mr. Chairman, that your highest incidence of increase in HPV is going to be among more sexually active women, which are going to be younger women; and that is not the group your program is targeting. I don’t say that as a criticism; I say that as an observation.

Ms. Lee. That is because we believe there are other Federal programs available to reach them and we know that they have much higher rate of recent Pap screening than older women.

Mr. Barrett. Thank you.

Mr. Bilirakis. Ms. DeGette.

Ms. DeGette. Thank you, Mr. Chairman. I would like to clarify the record a little bit.

I don’t think anybody intentionally implies in these hearings that women are reluctant to seek Pap smears or breast cancer screening as opposed to, say, men seeking treatment for prostate cancer, but in my experience, people—anybody who is fearful that they may have a cancer, a skin cancer or a breast lump, or something like that is going to be fearful about going in for screening, especially if they don’t have insurance.

Congressman Green talking about the Texan woman, Ms. Mondada, you know, people without insurance know that if they go in for screening and they have a cancer, they are going to be out tens of thousands or hundreds of thousands of dollars and that, in fact, it may bankrupt them; and so that adds to the natural fear of people going in.

I am wondering as we are seeing—I am wondering if you are seeing people in your outreach who are reluctant to come in for screening exactly for those economic reasons, even if there may be charity care available in their States?

Ms. Lee. We are told anecdotal reports from our program directors that this sometimes happens. It is documented in the study that we have alluded to that this is one of the barriers that they have. We at CDC have no other data than what we have obtained from the studies that we have alluded to.

Ms. DeGette. Is there anything you think can be done differently in outreach to try to increase the numbers of people com-
ing in for voluntary screening by overcoming those fears, either just the natural fear of having cancer or the financial fear of what diagnosis—or what treatment, in particular, will do?

Ms. Lee. Outreach is not the actual implementation and how you do outreach is not an area of expertise of mine, but I have talked with people who have. There is a lot of research that has been funded by the National Cancer Institute, for example, and then we know in our program that there is lots of effort at the local level to address those fears. The fear of finding cancer is very much one of the barriers that is identified over and over again, and our outreach workers in our States have developed strategies to address those fears.

Ms. DeGette. I know there are strategies, but yet you still have a small percentage who, for whatever reason, aren't coming in; or actually you have a fairly large percentage who aren't coming in.

Ms. Lee. I think that is mainly because we don't have the dollars to do any more.

Ms. DeGette. So you don't think that there is anything that can be done to improve outreach?

Ms. Lee. Oh, I think there is plenty that can be done. We can always do better.

Ms. DeGette. Can you give me a couple of specific examples? Maybe you can supplement your testimony.

Ms. Lee. Thank you.

[The following was received for the record:]

Outreach within the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is utilized to educate and motivate at-risk women to seek breast and cervical cancer screening and to minimize the barriers which impede access to these services for underserved populations. Both mammography and Pap tests are underused by women who are members of racial and ethnic minority groups, have less than a high school education, are older, or have low income. Studies have shown that these populations may not access preventive health care services if appropriate interventions are not provided. Many of the women who participate in CDC's program face significant barriers which diminishes their ability to obtain or understand the importance of these life saving services. Therefore, to be able to serve this population effectively, the program must minimize barriers through outreach activities by providing counseling, public information, education, translation services, and transportation.

CDC has developed a training on Outreach Strategies for Older Medically Underserved Women that has been provided to all State, tribe and territory programs funded through the NBCCEDP. The overall goal of the training program is to provide public education coordinators and outreach workers with the knowledge and skills to plan, select, and evaluate effective outreach strategies. Additional trainings for all 70 breast and cervical cancer programs funded by CDC are being provided over the next two years. CDC is also developing a train-the-trainer program to instruct local public education coordinators how to train other education and outreach workers on how to implement and evaluate local outreach efforts.

Each funded program provides outreach services based on the specific needs of their eligible population. With CDC's leadership, state-based programs have made significant progress in building state and community partnerships to reach women about the benefits of screening and early detection. Various outreach activities have been designed to educate women and motivate them to be screened. For example:

- **New Jersey's** state health department is collaborating with the University of Medicine and Dentistry of New Jersey and the YWCA to reduce screening barriers by offering educational outreach and access to screening. Program staff make monthly visits to senior housing complexes and other settings where women congregate (e.g., beauty parlors and supermarkets) to present an educational program designed for minority women aged 50 and older.

- **Nebraska's** Breast and Cervical Cancer Early Detection Program is concerned about cervical cancer in Vietnamese woman, who have the highest rate of cervical cancer of any ethnic group in the United States. In Hastings, Nebraska, the pro-
gram sent letters, in Vietnamese, inviting all Vietnamese women 18 and over to the local YWCA to learn more about cervical cancer and to receive referrals for screening services. Female interpreters were on hand for this event and during subsequent clinic visits.

- **Arkansas'** "Hats Off to Health" is a light-hearted but informative skit in which characters confront reasons women often give for not having breast cancer screening. Over 600 women have attended the program; surveys found that this non-threatening approach to breast cancer screening education was effective in reducing perceived barriers to mammography.

- **Massachusetts'** Breast and Cervical Cancer Initiative has established partnerships with a variety of community agencies already active in conducting outreach in racial and ethnic minority communities. Using a health circle model, groups meet in spaces that are familiar, accessible, and comfortable (e.g., homes, churches, and local agencies such as immigration offices). The health circle model has proved especially successful in promoting screening among older Southeast Asian women.

In addition to NBCCEPD, CDC funds a strong and effective network of partners that are well-positioned in communities at risk. These partners have developed projects that are focused on underserved populations and cover a wide range of public and professional education interventions. Projects include developing low-literacy, bilingual, and culturally appropriate educational materials that are used in diverse training and outreach programs and educational campaigns. The various interventions used by the different projects result in the common goal of increasing access to and use of screening services for priority populations.

**CDC funds the following partners to promote screening among populations at higher risk:** American Social Health Association; Association of Asian Pacific Community Health Organizations; Baylor College of Medicine, Salud en Accion Program; Institute for the Advancement of Social Work Research; Mautner Project for Lesbians with Cancer; National Asian Women's Health Organization; National Association of Community Health Centers; National Caucus and Center on Black Aged, Inc.; National Center for Farmworkers Health, Inc.; National Education Association Health Information Network; National Hispanic Council on Aging; U.S. Conference of Mayors' Research and Education Foundation; The Witness Project; and World Education.

CDC will continue to evaluate, expand and promote outreach services as resources will allow.

Ms. DeGETTE. Thank you, Mr. Chairman.

Let me ask a different question, which is I am wondering if—with the growing managed care system we have in this country, if you are having problems finding charity care providers to help implement this screening program. I know a recent *JAMA* article says there is a decline in charity care among providers in places where there is a high degree of managed care. Are you seeing this as well?

Ms. Lee. We have been told and that is documented in the report that that is one of the concerns that our States have is with the increasing changes in the health system. They are finding it more and more difficult because doctors have less autonomy about what, when and where they can provide charity care.

Ms. DeGETTE. Do you find this to be true across the board, or are there regional or rural versus urban issues?

Ms. Lee. We do not have information at that level of detail.

Ms. DeGETTE. Just one last question. I had thought that your program only screened women for breast cancer who were over the age of 50, and I thought I just heard you say you are doing over age 40.

Ms. Lee. We have always done over the age of 40. There was some—there has been—of course, as you know, there has been a big controversy in screening women 40 to 49. In 1994, we put out an official policy that encouraged our States to—of their breast cancer screenings to have 75 percent of them be among women 50 and over, and then the remainder could be for women 40 to 49.
Ms. DEGETTE. Higher-risk women?
Ms. LEE. Higher-risk women.
Ms. DEGETTE. Thank you. Thank you, Mr. Chairman.
Mr. COBURN. Mr. Chairman, I would just have a request to enter into the record, coming from the CDC, data that from 1990 to 1999 the screening program has screened 1.3 million women at a cost of $899 million.
Mr. BILIRAKIS. Without objection, it is part of the record. And I would say that we will be submitting written questions to follow up. I know Ms. DeGette and others have mentioned it and I know you won't mind receiving those, Dr. Lee, and responding to them.
We are advised that we will have three votes, which should take between 35 and 40 minutes at least. So, I am hoping we can release Dr. Lee before we break for those votes and hopefully during that break, we can grab a quick sandwich, and then can go right into the second panel.
As a second round, I have just one very brief question. I think it is important.
In the legislation before us, should we emphasize, and I hate to use the word “mandatory,” but in a mandatory sense to the States that might pick up this program, and add this to their Medicaid program in terms of case management? The significance of case management being what it is, should we basically require the States who choose to go into this program to create a case management type of a system so that we can ensure access to treatment?
Ms. LEE. I can't specifically address what you need to do in this bill because, again, that is not something that I am an expert in. But I will tell you that our program, as it exists, has as a feature, an integral feature, case management. We are providing additional funds to the program this year from the 1999 budget to augment their already-existing case management budget.
So case management is an integral part of our program, the NBCCEDP.
Mr. BILIRAKIS. Do you feel it should be an integral part of the State programs?
Ms. LEE. That is what I mean. It is an integral part of the State NBC programs as we already fund them.
Ms. ESHOO. Mr. Chairman, would you yield just for a moment?
Mr. BILIRAKIS. I would be glad to yield.
Ms. ESHOO. First of all, obviously we have Medicaid laws on the books, but specifically to this bill, we stayed away from a mandate. There is not a mandate in this bill. What it does is—what we tried to do is to motivate States to do more of what we are advocating for, and therefore with that motivation and the carrot, rather than a stick; so there is not a mandate in it.
Mr. BILIRAKIS. With the high percentage of Federal dollars involved here, though, the States would be receiving a much higher percentage than they ordinarily receive under—
Ms. ESHOO. It is a 75/25 split of funds.
Mr. BILIRAKIS. I am wondering if there shouldn't be some direction, in that regard. That is something we can talk about as we go along. All right.
Mr. Brown?
Mr. Brown. I have no further questions, and I think we want to get on with the second panel.

Mr. Bilirakis. Mr. Lazio?

Mr. Lazio. I just had one question because I know that twice Dr. Lee referenced this California pool of money $12.8 million, and I saw that in your written testimony.

I also saw in your written testimony the last line which I didn't hear in your oral testimony. Maybe I just didn't hear it, but it says, "Unfortunately, this fund is nearly depleted." so it is a one-shot fund, almost entirely depleted, and I just would not want to leave anybody with the impression that it is in any way sustainable and that again you are going to have to find care that is tantamount to $13 million that may not be found, and you may have more women in California continuing to slip through the cracks.

Mr. Bilirakis. I thank the gentleman.

Any further brief questions of Dr. Lee before we adjourn this panel?

Thank you so very much, Doctor. I appreciate your coming up here. You have been a lot of help. We will be checking back with you.

Ms. Lee. I can't imagine you wouldn't.

Mr. Bilirakis. All right, the second panel, if they will start to come forward.

Ms. Fran Visco; President of the National Breast Cancer Coalition; Susan Brown, President and CEO of the Susan G. Komen Breast Cancer Foundation out of Dallas, Texas; Ms. Carolyn Tapp, President, Women of Color of Breast Cancer Survivors Support Project out of Los Angeles; and Dr. Stanley Klausner from Sayville, New York.

Again, your written statements are a part of the record. You will have 5 minutes to present your oral testimony, just supplementing if you will or complimenting your written statements.

We will start off with Ms. Visco.

STATEMENTS OF FRAN VISCO, PRESIDENT, NATIONAL BREAST CANCER COALITION; SUSAN BROWN, PRESIDENT AND CEO, THE SUSAN G. KOMEN BREAST CANCER FOUNDATION; CAROLYN TAPP, PRESIDENT, WOMEN OF COLOR BREAST CANCER SURVIVORS SUPPORT PROJECT; AND STANLEY KLAUSNER

Ms. Visco. Thank you very much, Mr. Chairman. Thank you for your support of this legislation, for holding this hearing; and I also for your work on the Mammography Quality Standards Act.

I also want to very much thank Mr. Lazio and Ms. Eshoo for introducing this bill and for all of the members of the committee who are cosponsors and certainly the more than 260 Members of the House who are now sponsoring this bill.

The many members of the National Breast Cancer Coalition are thrilled that we all share the same goal, and that is to make certain that these women are treated and treated in a timely manner and that there is a system of care that they have access to.

Now, I have had breast cancer. I am a breast cancer survivor. I was diagnosed in 1987 when I was 39 years old. But I was very fortunate. I was also a partner in a law firm. I had access to qual-
ity medical care. But I can tell you the incredible pain, the worry, the fear, the anxiety, the not knowing which way to turn that I went through.

I can only imagine what women like Josefina go through, women like Mary Lee Matthews, who recently died of breast cancer and who was diagnosed through the CDC program and who had a very difficult time finally finding some treatment for her disease. I can only imagine what they go through. And I know that we are all here to make certain that we have no more Josefina that or Mary Lee stories.

You know, this issue bubbled up to the National Breast Cancer Coalition. Our membership is more than 500 organizations across the country, more than 60,000 individuals. And these organizations run support groups. They run outreach programs. They are educators. They are organizations that are involved in breast cancer and women's issues. They are hospitals. They are 500 organizations, and many of them contacted us about this incredible problem that they were having.

We heard story after story of my own organization in Philadelphia, the Linda Creed Breast Cancer Foundation, having to spend so much of its time finding and begging for charity care for women, finding and begging women to write checks to help get money to find treatment for these women. What they asked us to do is help find a system, a system of care for these women, a continuous system of care.

Jan Eick-Swigart was a well-to-do woman from California who had breast cancer. She died of her disease a couple years ago. But she spent the last 18 months of her life researching this issue, looking at various ways we can address the fact that there is a government program, a public health screening program, that has a gap, that is not whole, that has no treatment component attached to it. And she is the one who really brought to us the idea that finally became H.R. 1070 after much work, much analysis and much research. So I am really here in her memory and tribute to the work of Jan Eick-Swigart.

I know that we have highlighted to some extent the problems in the program as it exists, not in the screening program. We all think the screening component is a wonderful program. It is doing incredible work, and the people who are involved in that program are incredibly committed to our shared goal. But the study that the CDC funded tells us the problems. And, again, these problems were recognized by, as the study says, the experience and opinions of informed professionals affiliated with the program, and not the perspective of clients.

While they strongly supported continuing growth of the screening, they expressed several concerns: the considerable time and effort involved in developing systems for diagnostics and treatments; the process of identifying available resources within States; the lack of coverage for treatment services that negatively affected recruitment of providers. And they agreed that there are an increasing number of health care providers who are less likely and less willing to give charity care; the fact that there are women who do not come in for screening because they don't know what they will do for treatment; the fact that we want to have more screening, but
that is going to increase the problem that we have to correct while we correct the treatment problem.

The perspectives of the clients are what I want to briefly bring you.

I want to tell you that we hear from our member organizations who have actually held bake sales to raise money. They put together quilts and sold them to raise money to get treatment. But these women initiated treatment in this survey.

Mr. Bilirakis. Please summarize, Fran. I am sorry, but the bells have already rung.

Ms. Visco. I will summarize. And I think Josefina’s testimony summarizes it for all of us, and there are many like her. These women initiated treatment, but they are sitting with second mortgages and third mortgages. They are sitting with $40,000 in bills, with creditors knocking on their door. They are sitting with—begging the health care community to help them; and the health care community wants to, but the evolving health care system is harming them and is stopping them from doing this.

This is our opportunity to tell women and let them know we truly do share the goal of decreasing morbidity and mortality for women with breast cancer and cervical cancer by making this act law. That is the goal here. The goal is to get 1070 into law.

And I thank you very much for helping us do that.

[The prepared statement of Fran Visco follows:]

PREPARED STATEMENT OF FRAN VISCO, PRESIDENT, NATIONAL BREAST CANCER COALITION

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

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

BACKGROUND

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

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

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 compo-
It is the system that is broken, and we need to fix this problem so that they can screen more women, and not have to spend the majority of their time finding treatment services.

WHAT H.R. 1070 WOULD DO

NBCC-Personal Stories

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

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

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

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

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

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

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

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

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

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

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

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

CDC-Case Study

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

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

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

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

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

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

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

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

In the Context of an Evolving Health Care System

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

Mr. Chairman, I point you to a letter from Robert Brooks, MD, Secretary of the Department of Health for the Florida Department of Health and Human Services. (Mr. Chairman, may I submit this letter for the record?)

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

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

And the stories go on.

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

Florida, a state with the highest degree of managed care penetration in the country, is perhaps one of the best (but certainly not the only) example of a situation where the lack of availability of treatment can only get worse, and where any attempts to expand the screening program are hindered.
It is important to note that as managed care continues to expand across the country, more and more doctors may have less autonomy to provide the charity care relied on by NBCCEDP coordinators. To illustrate this point, a recent survey based on 12,000 U.S. physicians was published in the April 1999 issue of the Journal of the American Medical Association. The study finds that doctors whose income depends most heavily on health maintenance organizations and other managed-care health plans, on average, devote only half as much time to charity care as do their colleagues who don’t participate in managed care.

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

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

Precedent in the Medicaid Program

Respondents in CDC’s study suggest a similar solution to the lack of funding for treatment that we bring before you today—a solution that passage of H.R. 1070 would guarantee. That solution is a provision of treatment services assured through a federal “Medicaid option” which would give state Medicaid programs permission to allow eligibility to BCCEDP clients who are diagnosed with cancer through the program. This would include those women who are eligible for BCCEDP services but whose incomes and/or assets exceed Medicaid limits.

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

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

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

How This New Treatment Program Would Work

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

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

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

Mr. Chairman, and members of the Committee, thank you again for the opportunity to testify. We look forward to working with you on this critically important issue. I’d be happy to answer any questions you may have.
Mr. BILIRAKIS. Thank you very much.
Ms. Braun. Please pull the mike closer if you would.

STATEMENT OF SUSAN BRAUN

Ms. BRAUN. Good morning, Mr. Chairman—it is afternoon now—and members of the subcommittee. It is an honor to be here today and to speak before you.

Before beginning, though, I would like very much to recognize and honor the work of Congressman Lazio and Congresswoman Eshoo for the work that they have done, not only on this bill but also in the interests of breast cancer, which has been very significant and long-term.

I represent the Susan G. Komen Breast Cancer Foundation, which is dedicated to eradicating breast cancer. What I want to do is share with you the perspective as a funding organization and as a community outreach champion, because that is indeed what we are.

According to the Institute of Medicine, we are the largest private funder of breast cancer research; and we have raised and spent more than $200 million on breast cancer research, education, screening and treatment. In fact, we have paid for a number of the programs in the community that Fran discussed as well as the CDC’s efforts and other screening efforts in many communities.

I don’t tell you that to pat ourselves on the back, but to let you know that we think that the public has entrusted us with a great deal of their commitment to breast cancer, because we delve deeply into issues and because we do look substantively at any issue before we ourselves will fund it. And indeed, that is why almost 2 years ago we undertook to look at this very critical and important issue of treatment for women who are being screened and who do fall between the cracks of public and private insurance and who are not insured.

I agree wholeheartedly with the sponsors of this bill, and all of you supporters, as well as with Ms. Visco, that this is indeed a serious problem and one that we do want to see resolved. And we know that the last decade has been, as we have talked about here this morning, witness to a significant increase in the utilization of early detection services for breast and cervical cancer; and now we genuinely are challenged to ensure that the necessary diagnostic as well as treatment services are there for women who are indeed found to have these cancers and, hopefully, all others.

We conducted a study, and it is a general estimate of what the magnitude of the problem is, because that is something again to fund these issues at the local level. We are in 106 communities. We fund these things. So we need to know we are funding the right thing. Is this the best place to use our money? We estimated that approximately a thousand women screened through the program each year may require treatment assistance.

These are not only those within the 5 to 8 percent that Ms. Lee talked about from their study. Indeed, it may be a higher number; and we also estimate that there are a number of people within those numbers treated who also have to pay for a significant amount out of pocket. And so we like to calculate those in, too.
I think what concerned us as much as that in these estimates we also recognized that there are an estimated 20,000 women who are eligible for the BCCEDP program who are likely to develop breast cancer but who are not presently being screened. These may be women who aren't in touch at all with the health care system; and we feel that they, too, need to be brought into the health care system. And I know several of you have raised important questions about how to do that already today, so I don't think I need to go on with that.

I also would like to submit for the record, if I may, and you may already have copies, the testimony that was sent to us by the Bridge Breast Cancer Center which is in Dallas, Texas. It is a center that has served 1,700 women by linking physicians and facilities that provide diagnostic and treatment and recovery care for women with breast cancer. In 1998, they received a little over a million dollar in pro bono care from the professionals who serve the women. So there are programs out there.

[The information follows:]

PREPARED STATEMENT OF THE BRIDGE BREAST CENTER

We appreciate the opportunity to comment on legislation proposed in H.R. 1070 to provide assistance in the treatment of women diagnosed with breast cancer through a BCCEDP screening program.

The Bridge Breast Center is a non-profit organization founded in 1992 for the purpose of linking low income, uninsured women with diagnostic and treatment offices for breast cancer. Since its founding, the Bridge has served over 1750 women. We enjoy the support of twenty-two hospitals and clinics throughout our community and the "pro bono" services of 80 private physicians in the care of our clients. In 1998 we have received over $820,000.00 in donations and "pro bono" services totaling over $1,200,000.00.

It is our belief and a basic tenet of our program that the timely diagnosis and treatment of breast cancer requires the coordinated and cooperative effort of both the public and private sectors of the health community, and our success in North Texas substantiates both the wisdom and feasibility of this approach. Our ultimate success, however, is primarily limited by our lack of funds and other resources necessary to promote and conduct mammographic screening in the undeserved and uninsured women of our community. This, in turn means that our patients often present in advanced stages of the disease, greater resources are consumed in their treatment and outcomes are generally poorer than in those women disposed in a screening program.

It is this vital importance of screening mammography that prompts a particular concern in the proposed legislation. Any program design that might unintentionally divest funds and other resources for screening mammography to the treatment of patients may well produce a net negative effect. While we must provide for prompt and vigorous treatment of any women diagnosed with breast cancer and certainly welcome any and all funds to assist us, we must not do so at the expense of screening programs.

As importantly, care must be exercised to insure there are no disincentives that would curtail the willing and vigorous support of the private sector and local public agencies in the care of those women. Rather, we would encourage a program with the flexibility to enter partnership with community efforts to better address the needs unique to the women in every community.

Finally, if funds are made available for the treatment of Medicaid-eligible women, it seems antithetical to our mutual goals to limit those funds to women diagnosed in a BCCEDP screening program only. To do so would be a crippling, if not fatal disincentive to the few community-funded screening programs now existing. We respectfully urge that all eligible women be included, regardless of the manner in which the diagnosis is made.

Again we appreciate this wonderful opportunity to comment on legislation proposed in H.R. 1070. Thank you very much.
Ms. BRAUN. Nevertheless, I agree with the characterizations, and we all do, that it is in many cases patchwork. There are some very good programs. Those aren’t everywhere, and we recognize that. Not every State has had the good fortune that California had with the Blue Cross/Blue Shield moneys to create the treatment fund that existed in that State.

A couple of findings from the studies that we have initiated that we think are important is, as I said to you, yes, there are some very good—eight States have treatment programs, some States have model legislation, some States do actually provide some care through Medicaid, but this needs to be supplemented.

I will wrap up.

Also, we are concerned with the fact that the BCCEDP program reaches only about 15 percent of its targeted audience, and that leaves a number of women out there who, whether for reasons of fear of not being treated, having treatment resources, of not wanting to be detected and know the truth, indeed aren’t coming in touch with the health care system, where they might have at least a better chance for an early detection, a full treatment.

We have a number of different possible models that we looked at that might help out with this problem. Those are in our written testimony. And one of those is a Medicaid option for dealing with the needs of uninsured and low-income women. I have heard different things said today and earlier, and so I do want to clarify that the Foundation has not taken a position against this legislation and does not intend to do so. We were asked to come to this hearing today, we didn’t ask to do so, but rather we feel that it is important that since we have done some of this research and are a funder of programs in the community, a major funder, that we do feel like it is in the best public interest to share what we have learned.

Mr. BILIRAKIS. Thank you. Please wrap up, because we have got to vote.

Ms. BRAUN. Major points: Medicaid participation is optional in this bill—

Mr. BILIRAKIS. You can always do that during the questioning. Forgive me, but—you know.

Ms. BRAUN. All right. Then thank you very much for the opportunity to speak and ask me these questions later, and I will be happy to answer them.

[The prepared statement of Susan Braun follows:]

PREPARED STATEMENT OF SUSAN BRAUN, PRESIDENT AND CHIEF EXECUTIVE OFFICER, SUSAN G. KOMEN BREAST CANCER FOUNDATION

Good morning Chairman Bilirakis and members of the Committee: It is an honor to be offered the opportunity to speak before you today about the pressing issue of treating uninsured women with breast cancer. My name is Susan Braun, and I am president and chief executive officer of the Susan G. Komen Breast Cancer Foundation. The Komen Foundation was established 17 years ago by Nancy Brinker, in honor of her sister, Suzy Komen, who died of breast cancer at the age of 36. Our mission is to eradicate breast cancer by advancing research, education, screening, and treatment. To date, we have raised and spent more than $200 million toward this end. Our network of 106 Affiliates in 43 states and the District of Columbia, and the 35,000 volunteers that support them are conducting 98 Komen Race for the Cure® events this year. Last year, through the Race series and other fund-raising vehicles, we raised nearly $80 million.
It is not to pat ourselves on the back that I share with you these figures. Rather, it is to help illustrate to you the reach of the Komen Foundation and to demonstrate that “grass roots” is a way of being for us, not a mere cliche. Further, it is to establish the level of trust that we have earned with the public—trust that allows them to put a large sum of money in our hands with the assurance that it will be spent wisely in pursuit of our mission to eradicate breast cancer. We cherish that trust and work tirelessly to remain worthy. Komen affiliates work at the local level to build the public awareness of breast cancer and to establish the best settings possible for education and early detection. At a national level, we continue to establish programs to support our affiliates in these endeavors. In addition, we are (according to the Institute of Medicine) the largest private funder of research dedicated exclusively to breast cancer. Last year we funded 79 basic, clinical, and translational research grants, with grantees selected through a novel and well-respected blinded peer-review program. In addition we funded population-specific studies and postdoctoral fellows from our national grants fund for a total of over $17 million. Our affiliates granted another $25 million to local programs.

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

Statement of the Problem:

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

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

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

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

• Women diagnosed with breast cancer must be treated if they so choose, irrespective of their ability to pay.
• The quality of treatment they receive should be the highest possible.
• The time between diagnosis and initiation of treatment must be as short as possible.
• Care should be coordinated, ensuring the best care by the correct specialist.
• Care must not be short-term only; follow-up for at least five years is required.

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

Question One: What is the magnitude of need?

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

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

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

Reaching women who have been screened and diagnosed through the BCCCEDP with treatment assistance is more straightforward than reaching those who are not. Those who have been diagnosed within the program can be assisted by case managers, who will help find available services or a program that can provide special national, state, or local funds. Eight states have legislated breast cancer treatment funds, and local programs (such as “The Bridge” in Dallas) also exist. Pro-bono care

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<th>ESTIMATED ANNUAL NUMBER OF WOMEN IN THE US IN NEED OF FINANCIAL ASSISTANCE FOR THE TREATMENT OF BREAST CANCER</th>
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<tr>
<td>51,000,000</td>
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<td>23,664</td>
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| 23,664 | # of uninsured women, ages 35-64, potentially diagnosed with breast cancer each year |
| X 15 | Percent of women reached by the BCCCEDP |
| 3,550 | Potential number screened and diagnosed annually by BCCCEDP |
| X 05 | Percent not initiating treatment |
| 178 | Number of women with no treatment |
| 3,372 | Potential number screened and diagnosed annually by BCCCEDP who will initiate treatment |
| X 25 | Estimated percent enrolled in BCCCEDP paying out-of-pocket |
| 843 | Number of women screened and diagnosed through BCCCEDP who may need treatment assistance (excluding the 5% not initiating treatment) |
| 1,021 | Estimated number of women needing treatment assistance (women not currently getting treatment or those who are receiving treatment but may need additional financial assistance) [843 + 178] |
| 20,114 | Estimated number of women needing financial assistance for breast cancer treatment |

Notes: This model is based on simple estimates to begin the process of determining the magnitude of need and where the need exists. The model is for breast cancer only. The number of unemployed is likely an overstatement of the true BCCCEDP reach; thus total number of treatment may be a high estimate.
is provided in many communities. In the case of failure of these funding options, federal assistance may be required.

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

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

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

- Women are receiving treatment. Both the CDC and the Komen Foundation studies found that treatment was initiated for the vast majority of women who received a diagnosis of breast cancer. While imperfect and needing further resources, the system has been providing treatment for most women who need and want it.
- Patient navigator and case management services are critical in ensuring follow-up diagnostic and treatment services for women with suspicious screening findings. Case managers determine patient eligibility for assistance programs, including Medicaid and Medicare, identify and negotiate alternative sources of donated care, assist in obtaining and coordinating provision of support service needs, such as transportation and child care, and assist women in understanding and navigating an increasingly complex health care system. Such services are critical even in areas that have treatment funds and will continue to be necessary if states have an option to provide for treatment services under Medicaid.
- Provision of services reflects a delicate web of relationships and linkages across public and private organizations and across the federal, state, and local levels. Local communities are meeting the challenge of ensuring treatment services through the dedication of local health care and community professionals who donate services.
- The need for early detection services exceeds current levels of support. While the NBCCEDP has reached more than 1.3 million women with screening services, this represents only 12-15 percent of the women eligible for services in each state. Currently, state awards under the NBCCEDP range from $1.0 million to $5.0 million annually based on state population, the number of uninsured and underinsured low-income women, state capacity, and other factors. The need for early detection services outweighs current levels of support. Some partnerships between public and private organizations have been established to address the need for educational outreach and screening. Examples include the ENCOREplus program in St. Joseph, Missouri, which addresses barriers women face to health education and access to education and detection services and the Montana Department of Public Health and Human Services screening program.
- Innovative partnerships are being formed to address local treatment needs. Our study identified ten treatment funds established specifically to meet the needs of low-income uninsured and underinsured women. These included three privately funded (California Treatment Fund, Orange County Susan G. Komen Breast Cancer Foundation, and South Dakota Women’s Cancer Network) and seven state-funded programs (Arkansas, Georgia, Rhode Island, Maryland, North Carolina, South Carolina, West Virginia). These initiatives varied considerably in sources of support, structure, services covered, size and other important factors. They combined the unique local strengths of public and private sector partners and all were tailored to local circumstances. These local solutions generally are the result of partnerships between the government and private sector.

Actions for Success

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

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

• Community treatment models: Expand case management and public/private funds to strengthen and expand existing models.
• State treatment plans, which currently exist in some states: Model state legislation for treatment programs with federal demonstration project monies.
• Establish a Ryan White type program, which is used for HIV treatment.
• Use or enhance existing provisions with respect to state medical necessity provisions under Medicaid.
• Establish a Medicare adjunct program with a separate funding base.

Other comprehensive programs.

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

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

• Medicaid participation is optional in the proposed bill. States with limited funds in their Medicaid program may be reluctant to cover care for people who would otherwise be ineligible.
• Medicaid programs may be adverse to participate in an optional program that is diagnosis-specific (that is, only targeted for one disease). Although the mission of the Komen Foundation is focused only on breast cancer, we are aware of the needs of many people with other diseases who are covered by Medicaid.
• Medicaid varies considerably from state to state. Some states can afford more care than others can. An optional program that requires an initial investment on the part of states may be “picked up” only by the wealthier states. This may contribute to the variation in how a woman may be treated in one state compared to another.
• Eligibility for a Medicaid program may require women to spend down their resources before they qualify, and it is important that the financial status of patients undergoing treatment not be jeopardized.
• Medicaid eligibility only for women who are screened through the BCCEDP program does not account for the 85% of women who are eligible for the program but not reached. A certain percentage of these women, who may not be in touch with any healthcare services at all, will nonetheless develop breast cancer.
• Follow-up for breast cancer is standardly provided for at least five years following treatment. Any program that is medically sound must also provide for follow up.

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

Thank you very much for your time and attention.

Mr. BILIRAKIS. We will break until 1 o'clock.
Ms. Tapp and Dr. Klausner, forgive us. I appreciate the patience of everybody, but this is our world up here. Thank you.

[Brief recess.]

Mr. BILIRAKIS. Well, Ms. Capps is here. Ms. Eshoo is here. So we will get started. Mr. Brown I know is on his way.
Ms. Tapp, why don’t we go ahead and start with you? Please pull the mike closer.
STATEMENT OF CAROLYN TAPP

Ms. TAPP. Good afternoon everyone. I am Carolyn Tapp, and I am President of the Women of Color Breast Cancer Survivor Support Project in Los Angeles. I appreciate the opportunity of being able to speak on behalf of women of color and the underserved women in the Los Angeles area.

Many of the women who are in our group were screened through the CDC program, and they must have been the ones that fell through the cracks, because it wasn't as easy as I have heard, you know, to get treatment. Some of the women I know took about 6 months to actually get treatment. And I think this is just unheard of.

I know of one lady who was diagnosed, and the day she was treated she found out that she qualified for the program, she passed away the very next day. So it really didn't do her any good to go through this screening and all that. And a lot of women do voice the fact that why should they be screened when they don't get treatment? And most times when they get treatment it is inadequate treatment.

We are women who want to live just like everyone else in this country. This is a rich country, and we should be able to live and to go through the storm of breast cancer. I have known women who have had to borrow medication from other women in the group, because they couldn't afford to buy the medication. I know that I loaned many women some of my medication Tamoxifen especially, because they were left out to get this kind of medication, and it costs hundreds of dollars. So they couldn't afford to buy it. So we share.

And we share a lot of things together in the group. Our group—we have about 125 women in the group; and, last year, we lost 13 women to breast cancer. And this year we have lost four, including our vice president of the organization, Mary Lee Matthews.

The majority of the women last year were screened through the program or they had found some other kind of treatment, and this leaves our women vulnerable to groups of people who come out and say I have a treatment or I have a cure, and we can take care of you, and they are so open and so—knowing that they don't have money to be treated through the system, they go out and they get these different things—well, one thing is a kind of water they drink or some kind of root. And this is what is happening in our country.

And a lot of times they are never offered reconstruction. I have had women come in and tell me that they are using balloons with water to use as a prothesis. And this should not happen in our country.

And like the lady this morning said, we have a $12 million grant of moneys, that money ran out. She should have said we had and we have. We had it. We don't have it any more. So I don't know where to turn now when a woman comes in and tells me that she has been diagnosed or she is diagnosed through this program. I don't know where or how to turn or where to tell her to go, because this program is running out.

We must have adequate care for every woman in this country, no matter what her race is, what her financial standings are. We just must eradicate breast cancer, and we must have some type of
treatment, whether she is capable of paying or not, she shouldn't be turned down.

Because most women in my community are heads of households. They don't have money. They have to make decisions. Should I go and get a treatment or should I stay at home? And this is because they know that nothing is out there, nothing is out there. So we must have a bill to take care of all of our women. All of our women in this country deserve—I know I deserve and I know all of my women deserve adequate treatment.

Thank you.

[The prepared statement of Carolyn Tapp follows:]

PREPARED STATEMENT OF CAROLYN TAPP, PRESIDENT, WOMEN OF COLOR BREAST CANCER SURVIVORS SUPPORT PROJECT

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. The women we see often have to wait for care; or wait to see if they qualify for Medical (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 Medical so she could get treated. The Medical 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. No women get reconstructive surgery and have to live, not only with horrible scars, but also 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.

Mr. Bilirakis. Thank you very much, Miss Tapp.

The Chair recognizes Mr. Lazio for purposes of introducing Dr. Klausner.

Mr. Lazio. Thank you. It is with a great deal of pleasure and gratitude that I have the opportunity to introduce Dr. Klausner and also his wife who have traveled from Long Island to be here. She is a nurse in her own role.

I want to just mention that Dr. Klausner has really done a great public service, and he is a volunteer. He is in the trenches. He is a well-educated physician, and he got his medical degree through NYU. He is board certified, specializes in disease and surgery of the breast and currently is the attending surgeon and director of breast services at the Brookhaven Memorial Hospital, which is back on Long Island.

He is here today really to talk about his experience in treating women who suffer with breast cancer and particularly through the early detection program. In addition, as I said, to his long-standing practice, which is a successful practice, he has been a volunteer in helping poor and nonworking woman his entire career. For the last several years, he has worked with Suffolk County, my home county, and with low-income, uninsured woman who have been helped through the Federal screening program.

He is the founder and administers two breast cancer clinics located at community health centers in Amityville and Patchogue, which are low-income communities on Long Island. And he follows uninsured women through the process from screening to treatment and beyond, and he talks to them about their fear of having the disease, the anxiety about where to find treatment and where and how the bills will be paid, not to mention the emotional toll that these women face.

And I am again very grateful for the fact that the chairman has seen fit to invite Dr. Klausner, and Dr. Klausner has come. I am looking forward to his unique perspective.

Mr. Bilirakis. Thank you, sir.

Mr. Bilirakis. Doctor, you are on next.

STATEMENT OF STANLEY KLAUSNER

Mr. Klausner. Thank you.

I recently learned about H.R. 1070, and I felt compelled to speak to you in support of its enactment. I am not here representing any political or special interest group. I speak to you as a hands-on community surgeon and tell you of my experiences treating the population addressed by the bill that you are proposing, we call that the working poor.
In 1995, I became aware of the growing need to treat the working poor in my community who were unable to obtain comprehensive breast care at a local level. When diagnosis of breast cancer was made, particularly, and thankfully through the CDC program, these patients were referred to tertiary care facilities where they would have to literally work their way through the system.

Unfortunately, the care of breast cancer patients is multifaceted; and these patients were receiving inconsistent levels of care. At the time, I was asked by the administration of South Brookhaven Health Center to create a total care breast center which would take care of patients from start to finish. My task, besides developing the mechanics of a breast program, was to enlist a panel of—we will call them volunteer specialists who were willing to treat these patients, often for free.

There were numerous problems that occurred. The primary ones that we ran into were that physician services can be free, but durable medical equipment and supplies and drugs are not. This problem still exists. We were able to prevail, and this is a successful program currently, as Congressman Lazio mentioned to you. And at the end of my written statement, there is an exhibit labeled Exhibit A, which lists our statistics in treating the patients in our area who are the working poor.

Of note in that exhibit is the fact that 59 percent of our patients are uninsured. In 1995, when we started the program, there were 33 percent that were uninsured.

Now, I previously alluded to the fact that breast cancer is multifaceted and people have been talking about all the things that go into taking care of a patient with breast cancer. Once a diagnosis of breast cancer is made, it requires, and I wrote it out for you in more detail, a breast cancer surgeon, a medical oncologist, a radiation oncologist, a plastic surgeon, which is rare as hen’s teeth, prosthetics, not balloons filled with water, psychological counseling, and multiple support groups.

This is in addition to the typical stuff that everybody knows—pathology, laboratory, in hospital services and, remarkably, pain medications, which are not covered for these patients. All of these modalities must be in place in order for us to provide what the medical community has termed standard of care.

Having only a part of the services funded while somehow believing the patient can pay for the others to me is unrealistic.

A few things I would like to tell you, a disturbing trend has been emerging, and it has been touched upon here, with the advent and penetration of managed care, physicians are faced with new challenges. They have to see higher volume in order to maintain an acceptable bottom line, a fact of life. The free services they render to the working poor are straining their ability to adapt and making the breast program much more difficult to implement. I fear that, in the future, the altruistic feelings of my fellow physicians may be supplanted by the adage “charity begins at home.”

Even more disturbing, which was not touched upon, is I think, from my experience, the working poor are afraid to elect breast-conserving surgery. They are terrified of the medical bills, and their medical judgment becomes 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 knows that if she goes that route she—may I have another minute? She knows she has to go for chemotherapy, radiotherapy and the rest, and those bills become too expensive. What a difficult decision a woman must make when she opts to sacrifice her breasts rather than incur additional medical bills.

As for plastic surgical reconstruction, I have never yet been able to have that done on any patient I have treated.

I can continue giving you my personal experiences in treating the working poor and tell you of their courage and dignity. Unfortunately, it would take more than my allotted time, which I have already done.

Most simply put, these patients have been thrust into the health care 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 love to rally to right the wrongs. My cause is simply to be able to treat breast cancer 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. Thank you.
to treat these patients, often for free. Problems abounded especially when physi-
cian’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 ab-
stract 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 popu-
lation. 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 impor-
tant 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 proce-
dure such as a lumpectomy and axillary lymph node dissection.
• Medical oncologist to provide chemotherapy 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, labora-
tory, 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
starting to strain 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 physi-
cians may be supplanted by the adage “charity begins at home.”
Even more disturbing is my gradual awareness that the working poor are afraid to
consider 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 sur-
vive. 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:

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<tr>
<td>Patient visits:</td>
<td>534</td>
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<tr>
<td>Diagnostic procedures</td>
<td>113</td>
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<tr>
<td>Surgery</td>
<td></td>
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<tr>
<td>Mastectomy/resection</td>
<td>21</td>
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<tr>
<td>Other cancer treatment</td>
<td>6</td>
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Mr. BILIRAKIS. Thank you very much, Dr. Klausner. There are an awful lot and yet too few people like you in our society. There are a lot of volunteers in this country, a lot of pro bono work, and we are very grateful for that and for you.

Dr. Klausner, how would an optional Medicaid expansion, things that this bill would do, affect your pro bono work?

Mr. KLAUSNER. I think that touches on the heart of the difficulty. Remember, it is not a problem or has not been a problem for my colleagues who have supported me in this program to lend their time and efforts. When you ask an oncologist to treat a patient who desperately needs chemotherapy, who pays the thousands of dollars for the medications? This plan would pay for that. That is covered, and medications are covered service.

If a woman needs a breast prothesis if she has had a mastectomy, who covers that prothesis? Those are the kinds of the durable medical equipment and the medications alone are a good enough reason to move this forward. It gives the physicians the opportunity to be benevolent.

It is very hard to ask somebody, a plastic surgeon, to put in a prothesis and the prothesis costs $3,000. He is not going to pay for that, particularly if you line up 15 women. So I think that, just on the equipment, on the medications that are required, the bill would be beneficial. If, in fact, there was some remuneration for all of the pro bono work, it would make it more enthusiastic. Medicaid rates are not the standard of care—standard of payment in the communities, you have to know that.

Mr. BILIRAKIS. No, that is for sure.

Mr. KLAUSNER. However, physicians are willing to do that to take care of these patients. And that was my goal, to keep the patients from scattering around and seeking opportunities all around. When they live in a community that has good physicians, a good hospital, why can't they use it? So I honestly believe that would make a great step forward.

Mr. BILIRAKIS. Great. Well, you know, you bring up a point, and I am an early cosponsor of the legislation, and I do feel that something like this is needed. You heard during the prior testimony and the questioning, that we have only been able to reach approximately 15 percent of the eligible population as far as screening is concerned. So something has to be done, I think we would all agree, for improvement there, which would take additional funds.

Do you feel that if something like this program here were limited—I hate to use that word—were limited to drugs, prosthesis, other medical durable equipment, et cetera, that are so very expensive, that there would be enough volunteers out there to cover the rest of it, in other words, providers like yourself?
Mr. Klausner. I would like to say yes. Unfortunately, it has been covered over and over that the medical community is under great stress now to reorganize and readjust the way it practices.

Mr. Bilirakis. Sure. My son is a physician, I know what you mean.

Mr. Klausner. So is mine. He doesn't know what he is getting into. But the——

Mr. Bilirakis. He is learning.

Mr. Klausner. Yes. The issue really is the fact that it is very difficult to do charity work, pro bono work, work at markedly reduced rates, when you have to pay your staff, your rent and so on.

I think that making an effort, even if it is at the Medicaid level, the government is making that effort. It is putting the signal out to the physicians, if the government is moving funds in that direction, we have to meet them halfway, as was presented by the CDC. I mean, some of the suggestions that were recommended, find out payment plans. I mean payment plans, things like that, I think there has to be something to support our efforts.

Mr. Bilirakis. Thanks.

Let me ask you, Ms. Visco. Have you had any indication from the administration as to how they would address this problem?

Ms. Visco. The only information I have from the administration is what the CDC testified to this morning. And I didn't hear anything from the CDC that they would address this problem—that they are able to address this problem in any other way without legislation.

Mr. Bilirakis. Without this type of legislation?

Ms. Visco. Yes.

Mr. Bilirakis. I understand at least at this point they refuse to endorse the bill. Do you have any comments regarding that?

Ms. Visco. If the administration refuses to endorse the bill, the National Breast Cancer Coalition will take it to task; and they will hear from the members of the National Breast Cancer Coalition. They won't stop hearing till they endorse this bill.

Mr. Bilirakis. You don't know then whether they endorse or do not refuse to endorse the bill?

Ms. Visco. Right. We have had discussions with them, but we don't have an answer. Just the way you saw the CDC respond, discussions, but we don't have an answer yet.

Mr. Bilirakis. All right, thank you.

Mr. Brown.

Mr. Brown. Thank you, Mr. Chairman.

Dr. Klausner, we have heard over and over today only 15 percent of women who are eligible have been screened. You have said and others have said—and I apologize, Ms. Tapp, for not being back for your testimony—that if we were to increase the amount of money for screening that it would be very difficult, because already there is a squeeze on getting the number of physicians to donate services, that it would be very difficult to keep up, correct?

Mr. Klausner. Yes.

Mr. Brown. What have you found in the past that has been the most—for those people that have been screened and those who are diagnosed positive, what is the hardest service to provide? Is it the physician's time? Is it the chemicals for chemo? Is it prosthetic de-
sives? What have you found is the most difficult to bring in, in sort of a volunteer basis, a donated basis?

Mr. Klausner. Well, the reality of the situation is that medicine today is designed with a quarterback. Somebody has to organize and run a program. Somebody has to run the patient's care.

The problem with the working poor is that nobody has stepped up to the plate to do that. We do it in our health centers. Patients that I see and operate on are followed for life in the clinic. And we know that is going to stress the number of hours that we can see patients. But that is just the way it is.

Most of the people who volunteer under the CDC program for diagnostic work see the patient, do the diagnostic piece and the patient is cut loose. They now have to fend for themselves to find out where to go or they may make some nice suggestions. So I think that physicians have to be stimulated to take care of these patients as they do their private insurance-paying patients.

And, second, even if they do that, as I mentioned to you before, the costs of the equipment that we use is far and away more than what we charge, and those have to be addressed as well.

So I think you have to stimulate the physician to work to organize a patient through all of those steps. You can't do just a piece of it. If a patient is treated with a mastectomy or a lumpectomy and needs radiotherapy and doesn't get that, you might as well have done nothing. So all has to be done. It is a comprehensive package.

And I think that breast is one of the few conditions where that is truly the case. If there is a colon cancer, you take it out, you follow them, maybe with a yearly coloscopy, they are done. With breast, it is an ongoing process; and, besides, they have another breast.

So I think that it is not a simple answer, and it requires depth. It requires funding and it requires wisdom. And we need to do that.

Mr. Brown. What percentage of doctors, physicians in the community do you think do a significant amount of charity care today?

Mr. Klausner. Less and less. I can't tell you what the percentages are. We all do it. Everybody does it.

Mr. Brown. Do you think it is? 1 in 10? 1 in 5? That is a significant amount.

Mr. Klausner. A significant amount?

Mr. Brown. That is a few hours a week on the average.

Mr. Klausner. Five percent.

Mr. Brown. Is that any lower than 20 years ago? We all blame managed care on—saying that the managed care, there is less charity. Is there really?

Mr. Klausner. Yes. If I spend 45 minutes with a patient and I get paid nothing and you have three of those a day, how do you get by when the fees have been reduced? I mean, this is not the forum for that, but it is an economic fact. And, therefore, I don't blame the colleagues of mine who have become more reluctant to do the work they used to do more freely. They still do it.

Mr. Brown. Ms. Visco, do you want to answer that, too?

Ms. Visco. Yes I wanted to add, there is actually a study that has been published in JAMA in the April, 1999, issue that points
that out that, with managed care and the evolving health care system, the percentage of charity care is decreasing and decreasing rapidly. And I will make that available to the members of the committee.

Mr. Brown. Ms. Visco, what about the concerns that under this legislation that we will be treating women with breast cancer differently under Medicaid than other people with other diseases?

Ms. Visco. What we are asking for is a complete public health program, so we are not asking you to put every woman who doesn't have insurance in Medicaid. What we are asking you to do is to enact legislation that completes the existing Federal program. There is a screening program for breast and cervical cancer.

Screening alone does nothing. It needs to have a treatment component. So we are asking that the women diagnosed through that program be made Medicaid eligible at the same rate that they have to be eligible to get into the program to begin with. So we are not asking them to pay down anything. We are saying if they are eligible for screening, they should be eligible then for Medicaid treatment. That is why we are asking for breast and cervical cancer, because a Federal screening program exists.

Mr. Brown. Okay. Thank you, Mr. Chairman.

Mr. Bilirakis. Mr. Lazio to inquire.

Mr. Lazio. Thank you, Mr. Chairman.

Let me ask Dr. Klausner. You were here for the testimony of Dr. Lee, and you heard her testimony with respect to the survey results that they have in hand. Now, I wonder if you would be willing to comment on what that means to you and how do you square that with your experience?

Mr. Klausner. Well, I read the study, and in all due respect, when you want to do a study to find out the effects on women receiving proper care, it would seem to me those are the people you should be speaking to. In my experience, the patients who have come through the breast clinic are way out in terms of time that they have gotten to see me, 6 months to a year.

I would like to give you this for just an educational piece. From the time I do a breast biopsy, patients ask, how much time do I have to decide before I need to do something more definitive? What is the magical time? Well, that has been studied. It is about 6 to 8 weeks, which is enough time to get a lot of opinions. But, longer than that, you run the risk of this disease acting up again. All we did was a biopsy. We didn't do a curative procedure. Six to 8 weeks.

And patients come in a year after these things have been done, sometimes longer. Sometimes the referral slip is yellow. So, actuariably, I guess you can make any statistic you want. My experience has been quite the opposite.

Mr. Lazio. Does anybody else want to comment on the survey results and what they believe? Fran, do you want to?

Ms. Visco. It is hard for me not to respond to anything when I am given the opportunity.

Mr. Lazio. Here is the opportunity.

Ms. Visco. Clearly, here is Josefina Mondada, who is here from Texas. Here is one of those numbers. This is someone who initiated treatment, and she is now $26,000 in debt. The woman who was
going to be invited to testify from Virginia, a very similar circumstance. She initiated treatment. But her debt is astounding.

There are women who have creditors knocking on their doors; and there are women who initiate treatment but don’t follow through.

You heard the story that Ms. Tapp told you about sharing medicine. Women are not getting the treatment that they are supposed to get, because they have to share it among others. So the statistic, while it was a very important study, because it did tell us all of the problems and how fragile the system is, it is only numbers. It is the women who tell the story, and these stories are devastating.

Mr. Lazio. Doctor, because we didn’t have a chance to talk about these two clinics that you have founded and you now operate, tell us a little bit about that, if you can, and also what would be the impact be in terms of the breadth of service if you had a Medicaid option, if there was a Medicaid reimbursement in our backyard.

Mr. Klausner. The clinics are basically set up to be a referral center from the clinic system in Suffolk County. Physicians who have patients screened traditionally have to send them elsewhere. They didn’t exactly know where. They usually ended up at the larger tertiary hospitals.

We decided we would create a breast program at these centers which started out 1 day a month. It is now 2 days a week. And we see patients that are referred with positive mammogram, palpable mass, and we treat them from that point going forward.

The bill would be effective, because after I do my portion, which is surgery for a diagnosis and definitive care, sometimes they require—the lymph nodes are positive. They require chemotherapy. That is when we start running into problems.

I have an oncologist who does a lot of work for me in the private sector, so he is more apt to be favorable for this, but he has to fill out reams of paper to get medication under indigent—there is an indigent drug plan.

So here is a fellow I am asking to do something for free, and he is filling out reams of paper just to get the medicine to give to the patient. There are a lot of oncologists around they won’t do it for me, and I don’t blame them. They are not bad people.

Mr. Lazio. How about—you mentioned oncologist. How about radiologist, plastic surgeons? Are you having any more difficulty recruiting people who have these specialty areas that are also part of the continuum of service?

Mr. Klausner. Radiologists we don’t have a problem because they are part of the CDC program for diagnosis. I have not to this date in the 5 years that I have been doing the plan been able to get a woman reconstructed who has had a mastectomy since they are all choosing mastectomy or a great portion of them are choosing mastectomy, which really makes me wonder, but there is nothing I can do about it.

They have had a mastectomy, and that is the way they stay, because a breast prosthesis costs thousands of dollars and a Tram flap, which is a natural kind of prosthesis where they take a portion of the lower abdomen and graft it up there to create not a prosthesis, not official, but a real part of you, plastic surgeons
charge between 5 and $10,000 for that procedure. I am not getting that for free.

Mr. LAZIO. Thank you.

Mr. BILIRAKIS. Thank you.

Ms. Eshoo.

Ms. Eshoo. Thank you, Mr. Chairman. We have been in this hearing room for quite a while today, the better part of the day. As is often the case, each one of us listens but we look around. So as I continue to look around the room, I want to pay tribute to everyone that is here. I see a lot of badges and tags and all of that. I think they are real badges of courage because you—I know that you are all part of this effort and I want to salute you and you wouldn't be here unless you had experienced something. And I am sure that many of you have to travel a long way, spend a lot of money out of your own pocket so I want to acknowledge you and let you know that when I was looking around, I was seeing as well. It wasn't just a blank stare.

Dr. Klausner, you are really, I think, a man of great integrity and I would just like to make a comparison for especially the committee members. When I asked Dr. Lee to tell her story, it was done in a completely different way. I understand that because she is representing a program and comes out of an agency and there are all kinds of politics in and around all of that. People get territorial and then they get hingy because one has to answer to the other and there are all kinds of layers. Some of it is hierarchical and we all understand that; however, her language was the language of numbers and when we peel the onion skin back, those numbers are not how they were originally presented. Where they were originally presented—that 92 percent of the women that are screened get treatment—i.e., we don't need this bill.

In the language of this doctor, he has told us, as has Ms. Tapp, as has Fran Visco and I believe Ms. Braun, although I wasn't able to connect all the dots in your testimony when I read it, that it points to that it is not happening. And so I thank you, Doctor, for doing that because you did it through your own experience. You explained the shortcomings that are in the system, how we can do better. I can't help but think of something that my father said all of his life, and he lived a long, magnificent life and he was a great believer in this country, a great patriot. I used to ask him why he so believed in our system and government, in politics, in public service and he said, look, in this great country, there is only one class of citizenship. That is first class. We just have to make sure that we bring everybody to the same starting line so they can enjoy it.

So what you have pointed out really fits back into what my magnificent father said. We don't have to overcomplicate this. We can ask all kinds of questions and they are important to ask about the program, about the statistics, and all of that. You have provided, I think, the most powerful, powerful examples. Women are not looking for people to feel sorry for them and to have more charity in this country. Usually we are the care givers and the charity makers. So this isn't about feeling sorry for women. It is about, as Ms. Visco said, filling out and completing a program that the Congress began. It is as simple as that and it is profound as that.
mean for Ms. Tapp coming all the way from Los Angeles to say that women of color especially, need this bill. Because we know in poorer communities it is worse. I mean, aren’t we ashamed of that? Is that something to be proud of in this country? I was taught never to take someone else’s medicine. You don’t know what’s in that prescription. What may work for one body could be poison to the next person. And yet this is going on right now. And as Fran Visco so eloquently put it, this is the completion of a program. This is not favoritism. You never pit AIDS against breast cancer against cervical cancer against prostate cancer. We can address all of these things. The ingredient that is missing here in the prescription is political will.

So thank you for listening to my speech, but I picked up and I am inspired by what each one of you have said and this has been an outstanding panel and I think that you have really raised up in a very important and profound and practical way what we are trying to achieve here, and I thank you and I salute you and I pray we don’t disappoint you and the people you represent and take such good care of.

Thank you.

Mr. BILIRAKIS. Thank you. Ms. Capps.

Ms. CAPPS. Thank you, Mr. Chairman, and I realize I am sort of winding things up here. I was just joined by some constituents briefly from San Luis Obispo, California, and it is a rural county, and I am going to make just the comment that the issues that we have been talking about, finding services for women with this particular tragedy in their lives. Dr. Klausner, you are eloquent as you have portrayed for us some of the range of needs that women have and I might mention that if you happen to come from a rural area, any of the rural areas across our country, the frustrations and the difficulties can be compounded by lack of services available. I am so impressed with this panel and I thank you, each one, for participating. You have given life and blood to the cold numbers that we have heard previously and I am convinced that the organizations that you represent, the National Breast Cancer Coalition, the Susan G. Komen Foundation, and the Women of Color Breast Cancer Survivors Support Group, you are the reason this bill is now in legislation. You have given us the impetus, the motivation to do our part and there are various pieces to be—roles to be played and I want to hear—I am going to ask Ms. Tapp, if you would start at least, you were so eloquent in talking about the women whose lives you are intertwined with because you even shared your medication with them. You got us to this point.

If we should pass and be so fortunate to pass this legislation, your work is not going to be finished. We are not taking the place of this network because it is such a complex situation that it is going to take everything that all of us can do and it is about partnerships, is what it is about. It is really just about us doing our part and you have the bulk of the work still to do at the community, at the grass roots level. And Ms. Tapp, if you could respond to that. If we can pass this bill, then how can you see yourself relating to your sisters at home?

Ms. TAPP. Well, if this bill is passed, I can see more of my sisters living. They won’t be dying at such young ages like age 25, 27
years old. If this bill is passed, we won't have to get out and scramble around looking for a place to send them when they are diagnosed. We will have a stationary place and it will help in the long run.

Ms. CAPPs. So you will still keep up your work of supporting them because that is still going to need to happen and maybe even finding some of the other pieces to put in place.

Ms. TAPP. As president of the organization, I am not a paid person. I am a volunteer and dedicated to what I do, because I know what I went through and I wouldn't want anyone to go through the things that I have gone through or see the things that I have seen. So I am dedicated to the work that I do.

Ms. CAPPs. Maybe someone else since the buzzer hasn't gone off. If you would like to respond, please, Ms. Braun.

Ms. BRAUN. I would hope that we could see even more women who would live as a result of these efforts by including that 85 percent who are not yet touched in this health care system, you know, treating the huge majority of need there and that we also recognize that as an optional program, perhaps the very poorest of States—Mr. Green brought this up earlier—may not indeed accept that option. States often don't accept Medicaid options that are available and we do want to be sure that the women who are screened are treated so that we have to be sure that we are closing the full gap.

So I would urge whatever action is possible on behalf of the committee to ensure that those gaps are closed as well to work with us to do that, that not just the women who come through this particular program but any program who are screened and diagnosed and not able to may have assistance.

Ms. CAPPs. If I could make a last comment. The whole purpose of the early detection and screening program is cost savings. It is so much easier in terms of women's lives and also money, resources to get in there quickly with a tiny little lump and that first stop and the treatment then, as you said, Dr. Klausner, 6 to 8 weeks and then we are fine. But 6 months, then it is so expensive.

Thank you so much.

Mr. BILIRAKIS. You have been a terrific panel. You are the grassroots and so important. It is just like I guess Ms. Tapp, somebody, made a comment about the CDC inquiring to see if the program treatment is working and that sort of thing but did they in fact check with the actual people who are receiving the treatment. And so you have helped us an awful lot in that regard. We will have additional questions of you and we will submit them to you in writing. We would request appropriate responses if you would, please.

Before we adjourn, I would like to announce that the Subcommittee on Energy and Power, that I also sit on, has a hearing scheduled in this room following this hearing and it would be appreciated if the audience and our witnesses would vacate the room as quickly as possible so that the room could be reset for that hearing. Thank you for your cooperation. Thanks for your patience.

Ms. ESHOO. Mr. Chairman, would you yield to me for a moment?

Mr. BILIRAKIS. I would be glad to.

Ms. ESHOO. I want to once again thank you for holding the hearing. We all know that a hearing does not make a bill. And so you can tell what my next question is going to be. What do you intend
to do relative to moving this to a markup? I know that there are
timeframes to be considered. I think that much has been flushed
tout today. I know that you will keep in mind when you speak to
the chairman of the full committee, Mr. Bliley, that 75 percent of
the Commerce Committee are cosponsors. So it is not that Con-
gressman Lazio and I are being pesky flies in this and that there
are only two. It is more than the majority of this powerful com-
mittee.

Mr. Bilirakis. I pointed all that out to him before this hearing.

Ms. Eshoo. Can you give us some—-

Mr. Bilirakis. I can't do that. You should know better than that.

Ms. Eshoo. I don't know. That is why I am asking.

Mr. Bilirakis. We have at least one markup, maybe two next
week. We have a couple of hearings scheduled. We have managed
care legislation that we trust is going to be rearing its head during
the next few days, whether it be in this subcommittee, full com-
mittee, on the floor. We don't know yet. Any further addressing at
this legislation is going to be starting in September, in the fall ob-
viously. It can't take place in the next 2 weeks because we have
of course the break coming up.

Ms. Eshoo. We will be ready.

Mr. Bilirakis. I think that we all believe that something more
needs to be done here. Obviously we all have parameters that we
have to work under. But with the hearing like this and the help
that we have got from you and the testimony and what not, it has
eased it I think tremendously. Thank you.

Ms. Eshoo. Thank you, Mr. Chairman.

[Whereupon, at 2 p.m., the subcommittee was adjourned.]