

**Carolyn Tapp
President
Women of Color Breast Cancer Survivors Support Project
Los Angeles, California
July 21, 1999**

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

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

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

is where we come in — to help connect them with those services and to provide support

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

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

This just isn't right. Women should be able to make decisions about their treatment

based on good medical recommendation -- not based on fear because they can't afford treatment like chemotherapy and radiation.

I would also like to tell you about the many women who do get treated -- some at public facilities -- that receive horrible inadequate care. Some women we see are talked into radical mastectomies because the physicians know they don't have insurance and can't pay. 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.

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Testimony of
Stanley Klausner, MD, FACS
On Behalf of H.R 1070, a Bill to Amend Title
XIX of the Social Security Act.

Submitted to Committee on Commerce

U.S. House of Representatives

July 21, 1999

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

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

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

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

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

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

- **Medical oncologist** to provide 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, laboratory, in-hospital services and even pain medications**. All of these modalities must be in place in order to provide “**standard of care**” for the breast cancer patient. Having only a part of these services funded, while somehow believing the patient can pay for the others, is unrealistic.

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

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

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

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

I thank you for your attention.

Exhibit A

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

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

**Testimony by Josefina Mondada
Yancey, Texas
July 21, 1999**

Good Morning. My name is Josefina Moncada 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 recommended 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 -- and there is still no coverage. What if I 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.

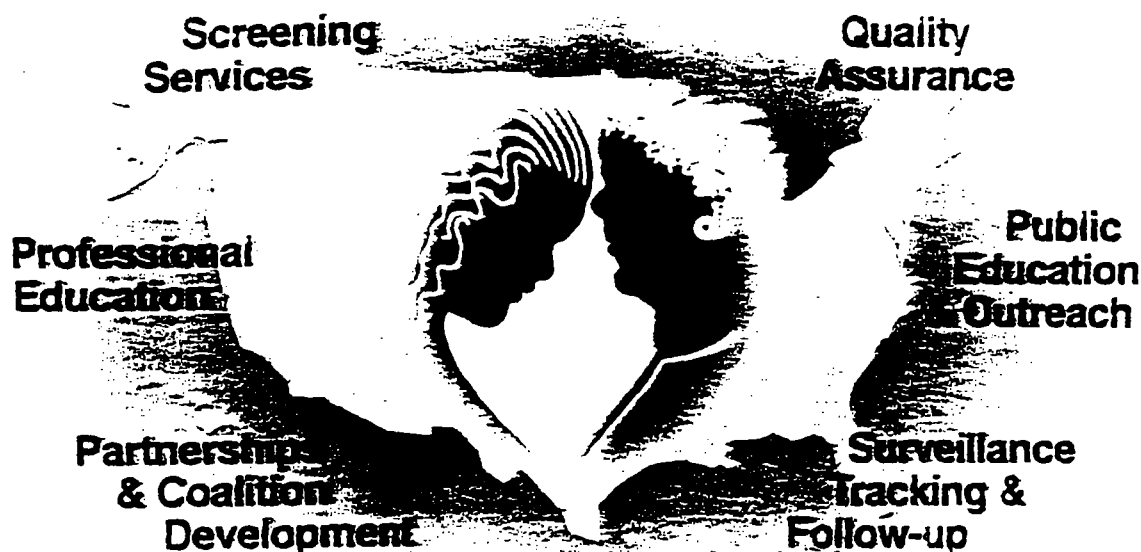
Mr. Chairman, members of the Committee, I feel lucky I got treated, but that is only one part of the story. I worry every day about how to pay these bills. I simply don't have the money.

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.

The National Breast and Cervical Cancer Early Detection Program

AT-A-GLANCE
1999



"Over 1.2 million women have taken advantage of services provided through CDC's National Breast and Cervical Cancer Early Detection Program. Less than a decade old, this program now operates in every state in the country, providing recommended screening to low-income women. Yet we are still only able to reach 15% of the eligible population. As a nation, we must step up our commitment to reaching all women."

Jeffrey P. Koplan, MD, MPH
Director, Centers for Disease Control and Prevention



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention



Breast and Cervical Cancer Screening: Preventing Unnecessary Deaths Among Women

An estimated 2 million American women will be diagnosed with breast or cervical cancer in this decade, and half a million women will lose their lives to these diseases. A disproportionate number of deaths will be among women of minority and low-income groups.

Many of these deaths could be avoided by making screening services available to all women at risk. Such screening measures could prevent approximately 15%–30% of all deaths from breast cancer among women over the age of 40 and virtually all deaths from cervical cancer.

Excluding skin cancer, breast cancer is the most common cancer among American women and is second only to lung cancer as a cause of cancer-related death. An estimated 175,000 new cases of breast cancer among women will be diagnosed in 1999, and 43,300 women will die of this disease.

The incidence of invasive cervical cancer has decreased significantly over the last 40 years, in large part because of early detection efforts. Even so, an estimated 12,800 new cases of invasive cervical cancer will be diagnosed in 1999, and 4,800 women will die of this disease.

In most cases, the earlier breast cancer is detected, the better the survival rate. When breast cancer is diagnosed at a local stage, the 5-year survival rate is 97%. When breast cancer is diagnosed after it has spread, the 5-year survival rate decreases to 21%.

Benefits of Screening

Mammography is the best way to detect breast cancer in its earliest, most treatable stage—an average of 1.7 years before the woman can feel the lump. Mammography also locates cancers too small to be felt during a clinical breast examination.

The primary purpose of **cervical cancer screening**—which is performed by the Papanicolaou (Pap) test—is not to detect cancer but to find precancerous lesions. Detection and treatment of such lesions can actually prevent cervical cancer.

Cervical cancer screening also offers great benefits. For a woman found to have precancerous cervical lesions or to have cancer in its earliest stage, the likelihood of survival is almost 100% with timely and appropriate treatment and follow-up.

CDC's National Breast and Cervical Cancer Early Detection Program

Recognizing the value of screening and early detection, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990. This act authorized CDC to provide critical breast and cervical cancer screening services to underserved women, including older women, women with low incomes, and women of racial and ethnic minority groups.

Through its landmark National Breast and Cervical Cancer Early Detection Program (NBCCEDP), CDC now supports screening activities in all 50 states, in 5 U.S. territories, in the District of Columbia, and through 15 American Indian/Alaska Native organizations. By October 1997, more than 1.5 million screening tests had been provided by the NBCCEDP.

Fiscal year 1999 appropriations of approximately \$153 million enable CDC to establish greater access

to screening and follow-up services, increase education and outreach programs for women and health care providers, and improve quality assurance measures for screening. Despite its success in screening more than a million women, with existing resources the NBCCEDP is able to screen only 12%–15% of the eligible population for these two cancers.

The legislation for NBCCEDP does not authorize CDC to pay for treating breast and cervical cancer. However, 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 state and local government support, the generosity of medical providers, and the commitment of communities.

CDC'S National Leadership

Screening alone is not sufficient to prevent unnecessary illness and death. Essential technical and scientific underpinnings must be in place at the national level to support state-based programs. CDC collaborates with state health agencies, professional and voluntary organizations, academia, and other federal agencies to ensure that the following elements are in place to serve as resources for states:

- Quality assurance.
- Program tracking and evaluation.
- Professional education.
- Public education and outreach.

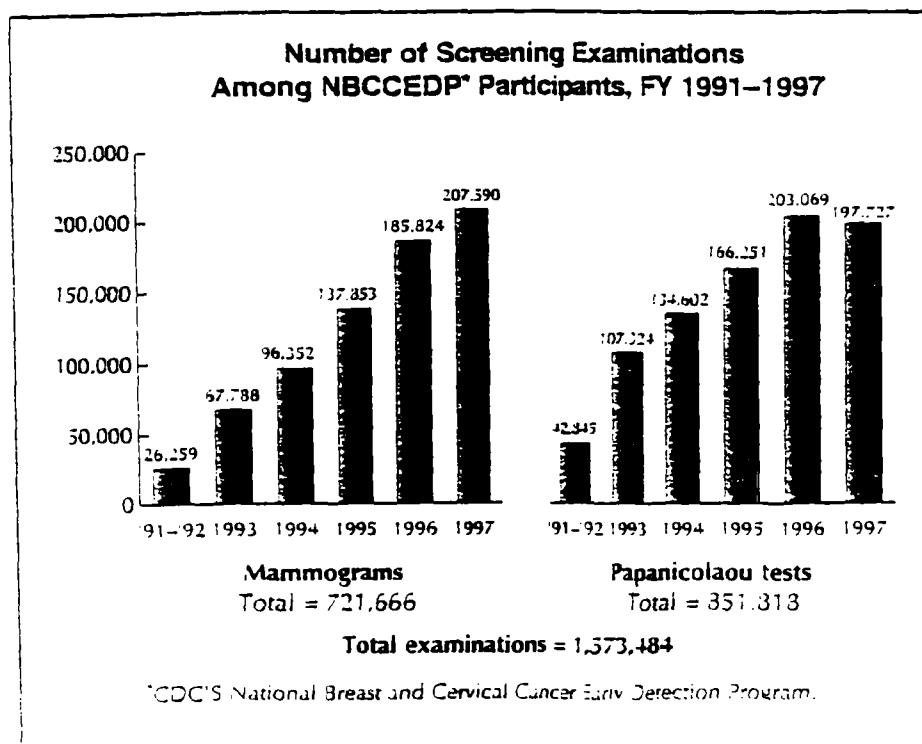
Ensuring Quality Screening and Follow-Up Services for Women

Quality assurance is essential if screening for early detection is to be an effective tool for controlling cancer. To help ensure the quality of the screening and follow-up process, CDC has collaborated with the American College of Radiology to improve and certify the quality of mammography screening, developed guidelines on the evaluation of common breast problems, used program data to monitor health outcomes, and issued recommendations on a public health response to the regulatory closure of cervical cytology laboratories. In addition, CDC provides

screening and diagnostic guidelines to all state-based programs and assists states in evaluating their clinical services.

CDC recently evaluated how early detection programs in seven participating states (California, Michigan, Minnesota, New Mexico, New York, North Carolina, and Texas) developed strategies to obtain resources not only for diagnostic services, for which the NBCCEDP provides funding, but also for treatment services, which the NBCCEDP requires participating states to provide but cannot (by law) reimburse. Results of the study indicate that treatment had been initiated for almost all NBCCEDP clients in whom cancer was diagnosed. However, the programs pointed out that the approaches used to obtain these services were short-term, labor-intensive solutions that diverted resources away from screening activities.

As more women are screened by the NBCCEDP, participating health agencies and providers will experience greater challenges in obtaining sufficient resources for treating women with breast and cervical cancer. CDC has expanded its case management services to help women overcome financial, logistical, and other barriers to these services. However, more formalized and sustained mechanisms need to be instituted to ensure that all women screened have ready access to appropriate treatment and follow-up.



Tracking Program Outcomes

To better target critical screening activities, CDC works with states to collect critical information to monitor program progress in reaching women and detecting cancer. Since its inception, the NBCCEDP has

- Provided over 700,000 mammograms to women. Of this number, over 48,000 were abnormal, and over 3,600 cases of breast cancer were diagnosed.
- Provided over 850,000 Pap tests. Of these, over 25,000 were abnormal and over 26,000 cases of precancerous lesions were diagnosed. Over 400 cases of invasive cervical cancer were diagnosed.

CDC also provides and tracks diagnostic evaluations for women who have had abnormal results through screening initiated by providers not involved with the NBCCEDP.

Public Education and Outreach: Eliminating Barriers to Screening

CDC collaborates with health care professionals and organizations, human service and voluntary organizations, academia, and health agencies participating in the program to address barriers to screening.

National Collaboration

Examples of CDC collaboration with national organizations include the following:

- CDC collaborates with the American Cancer Society (ACS) to develop and disseminate comprehensive information on cancer prevention and early detection. Through CDC, ACS divisions have formed partnerships with state health departments to increase screening services to medically underserved women. CDC and ACS collaborate in many programmatic areas, including establishing program infrastructure and public and professional education activities.
- A unique public-private partnership was established among CDC, Avon Products Inc., the YWCA of the U.S.A., the National Alliance of Breast Cancer Organizations (NABCO), and the National Cancer Institute. Avon's Breast Cancer Awareness Crusade has raised more than \$25 million for breast cancer programs nationwide

Barriers to Screening

Fear. Women may be afraid to discover that they have cancer.

Cost. Many women cite cost as the reason they do not use early detection programs. Many are not aware of the availability of low-cost programs.

Lack of Transportation. For many women who lack transportation, convenient location of screening facilities is important.

Communication Barriers. Communication styles and methods appropriate for one group may be inappropriate for another.

Lack of Physician Referral. Studies have shown that women are more likely to be screened if their physician recommends screening.

Lack of Child Care. Some women need assistance with arranging child care to be able to use screening services.

through the sale of its Breast Cancer Awareness pink ribbon products. Since 1993, about 300 community-based programs in 49 states and Puerto Rico have received funding from Avon's program through the YWCA of the U.S.A. and NABCO to educate women about breast cancer and to provide underserved women with access to early detection services. Beginning in 1998, all funding of community-based programs was consolidated under the Breast Health Access Fund administered by NABCO.

States Take Action to Educate Women.

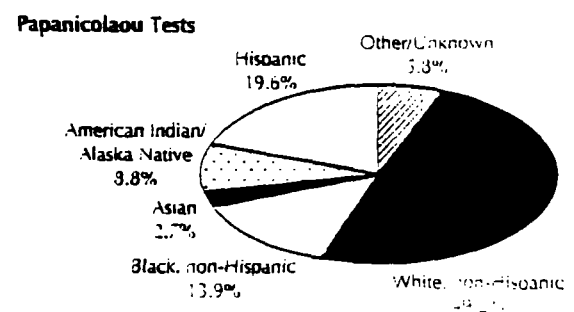
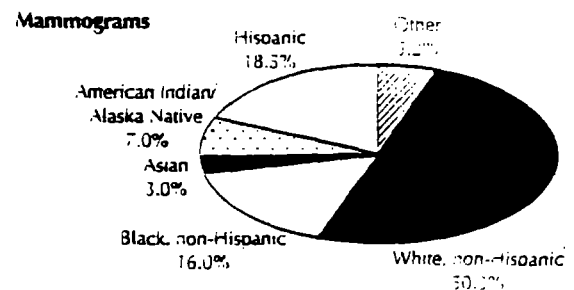
With CDC's leadership, state-based programs have made significant progress in building state and community partnerships to reach women about the benefits of screening and early detection. Various outreach activities have been designed to educate women and motivate them to be screened. For example,

- 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 and to schedule appointments for screening in a mobile mammography unit that comes to the site 2 weeks later.
- 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 nonthreatening 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.
- Washington, D.C.'s breast and cervical cancer program has recruited a woman minister to work with Project WISH to raise breast health awareness in the faith community. Over 20 activities have been implemented, including the

hosting of prayer breakfasts, workshops and forums, and pink ribbon teas; the distribution of literature and pink ribbons; and the publication of announcements in religious bulletins. In addition, on Sundays activities focusing on screening awareness have been conducted with testimonies from survivors and educational talks on breast health.

- The Cherokee Nation of Oklahoma has developed an educational video on the importance of breast self-examination for American Indian women. Funded through the Avon Breast Health Access Fund, the video highlights three American Indian cancer survivors advocating for early detection through breast self-examination.

Percent Distribution of Screening Examinations Among NBCCEDP* Participants, by Race/Ethnicity, FY 1991-1997



*CDC's National Breast and Cervical Cancer Early Detection Program.

Partnerships for Cancer Control in Populations at Higher Risk

Partnerships that focus their prevention efforts on those at greater risk are essential for understanding and alleviating disparities. 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 live below the poverty level.

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. For example, many projects are involved with 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.

Professional Education: Enhancing Health Care at the Source

Professional education is designed to enhance the quality of care that women receive. Through education, the NBCCEDP has assisted a wide range of health care professionals—including physicians, nurses, radiology technologists, and cytologists—to better understand their key roles in the early detection of breast and cervical cancer.

In 1998, CDC's National Training Center provided two training programs and one self-study informational packet for health professionals. For 1999, CDC is developing a self-study packet on follow-up of abnormal findings from clinical breast examinations and mammograms and a workshop and self-study packet on evaluation-based work plans that will assist personnel in state and local health agencies and tribal organizations.

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
World Education

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National Center for Chronic Disease Prevention and Health Promotion, Mail Stop K-64,
4770 Buford Highway NE, Atlanta, GA 30341-3717, (770) 488-4751.
Voice Information System: 1 (888) 842-6355 Fax: (770) 488-4760
cancerinfo@cdc.gov <http://www.cdc.gov/cancer>

THE BREAST AND CERVICAL CANCER TREATMENT ACT

The NBCCEDP

- In 1990, Congress enacted the **National Breast and Cervical Cancer Early Detection Program (NBCCEDP)** into law (P.L. 101-354), enabling states to provide breast and cervical cancer screening services to women with no other source of payment for such services.
- The program is administered by the **Centers for Disease Control and Prevention (CDC)**, and works in partnership with state and local health agencies and other community partners to provide education, outreach, screening services, and follow-up care. NBCCEDP serves older women, women with low income, uninsured or underinsured women, and women of racial/ethnic minority groups who qualify.
- Congress appropriated **\$159 million for FY 1999 for the NBCCEDP**. The program is now in all 50 states, the District of Columbia and 13 American Indian/Alaska Native organizations; however not all state programs are fully functioning.

The Success of the Screening Program

Since the NBCCEDP's inception through March 1998 it has:

- Provided mammography screening to 794,445 women aged 40 years and older;
- Found 56,119 (7%) abnormal mammograms;
- Diagnosed 4,137 cases of breast cancer; and

Of those diagnosed with breast cancer, 3,350 were under 65 years of age - and ineligible for Medicare coverage.

Current Approaches to Providing Treatment

- As enacted by Congress, the NBCCEDP provides funding only for screening services. Recently CDC agreed to cover diagnostic services- services necessary to determine whether or not a woman has breast cancer. However, there is still no federal funding to provide treatment services to the 3,350 women under age 65, who have been screened and diagnosed with breast cancer.
- The current system for treatment is an ad hoc patchwork of providers, volunteers, and local programs scrambling to find treatment dollars. Although health agencies at the state and local levels and breast cancer advocates have found creative ways to help women find treatment, these networks are overloaded and increasingly unreliable. Women are forced to rely on charity care, donated services, and bake sales to pay for their treatment.

- **The lack of financial support for treatment is hurting the NBCCEDP.** Time and effort required to arrange for treatment services have begun to divert resources away from screening activities. As a result fewer women are being screened-the program serves only 12% to 15% of age-eligible, uninsured women nationally.

A Long-term Solution: Covering Treatment Costs Through the Medicaid Program

- **The National Breast Cancer Coalition (NBCC) believes that women should not have to hold bake sales to fund breast cancer treatment.** NBCC believes it is irresponsible to enact a federal program that promises to reduce the number of deaths from breast and cervical cancer and not guarantee federal funding for treatment services to women who have been screened and found to have breast or cervical cancer.
- **Medicaid is the answer.** Congress should allow states the option of providing women diagnosed with breast or cervical cancer through the NBCCEDP, Medicaid coverage for their disease.
- **There is a precedent for covering participants in the NBCCEDP under Medicaid.** In 1993, Congress created the Tuberculous Optional Benefit Program, making individuals who are infected with tuberculosis eligible for Medicaid.

Summary of the Breast and Cervical Cancer Treatment Act

- The bill would establish an optional State Medicaid benefit for coverage of certain women who are screened and diagnosed with breast or cervical cancer under Title XV of the Public Health Services Act's NBCCEDP.
- To be eligible, women would have to satisfy the income and resource eligibility requirements established under NBCCEDP; be under the age of 65; have been diagnosed with breast or cervical cancer under the Title XV Program; and not otherwise have health insurance coverage.
- Women who qualify for NBCCEDP would be allowed presumptive eligibility for Medicaid coverage for the duration of the treatment of their breast and cervical cancer.
- States electing to provide breast and cervical cancer treatment as an optional benefit would receive an enhanced match to encourage participation in establishing this benefit.

The Breast and Cervical Cancer Treatment Act

S. 662/H.R. 1070

Bill Summary

- The bill would establish an optional State Medicaid benefit for coverage of certain women who were screened and diagnosed with breast or cervical cancer under title XV of the Public Health Services Act's National Breast and Cervical Cancer Early Detection Program (NBCCEDP).
- To be eligible, women would have to satisfy the income and resource eligibility requirements established under NBCCEDP; be under the age of 65; have been diagnosed with breast or cervical cancer under the title XV Program; and not otherwise have health insurance coverage.
- Women who qualify for NBCCEDP would be allowed presumptive eligibility for Medicaid coverage for the duration of the treatment of their breast and cervical cancer.
- States who elect to provide breast and cervical cancer treatment as an optional benefit would receive an enhanced match to encourage participation in establishing this benefit.

S 662 IS1S

(Star Print)

106th CONGRESS

1st Session

S. 662

To amend title XIX of the Social Security Act to provide medical assistance for certain women screened and found to have breast or cervical cancer under a federally funded screening program.

IN THE SENATE OF THE UNITED STATES

March 18, 1999

Mr. CHAFEE (for himself, Ms. MIKULSKI, Mr. MOYNIHAN, Ms. SNOWE, Mr. SMITH of Oregon, Mr. HARKIN, Mr. COCHRAN, Mr. DURBIN, Mrs. MURRAY, Mr. LEAHY, Mr. ROCKEFELLER, Mr. LIEBERMAN, Mr. LAUTENBERG, Mrs. FEINSTEIN, Mr. BINGAMAN, Mr. SARBANES, Mr. HOLLINGS, Mr. WELLSTONE, Mr. CLELAND, Mr. KENNEDY, Mr. JOHNSON, Mr. ROBB, Mrs. BOXER, Mr. REID, Mr. KERREY, Mr. COLLINS, Mr. CONRAD, Mr. BAYH, Mr. INOUE, Mr. TORRICELLI, Mr. REED, and Mr. DODD) introduced the following bill; which was read twice and referred to the Committee on Finance

A BILL

To amend title XIX of the Social Security Act to provide medical assistance for certain women screened and found to have breast or cervical cancer under a federally funded screening program.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. OPTIONAL MEDICAID COVERAGE OF CERTAIN BREAST OR CERVICAL CANCER PATIENTS.

(a) COVERAGE AS OPTIONAL CATEGORICALLY NEEDY GROUP-

(1) IN GENERAL- Section 1902(a)(10)(A)(ii) of the Social Security Act (42 U.S.C. 1396a(a)(10)(A)(ii)) is amended—

(A) in subclause (XIII), by striking `or' at the end;

(B) in subclause (XIV), by adding `or' at the end; and

(C) by adding at the end the following:

`(XV) who are described in subsection (aa) (relating to certain breast or cervical cancer patients);'.

(2) GROUP DESCRIBED- Section 1902 of the Social Security Act (42 U.S.C. 1396a) is amended by adding at the end the following:

`(aa) Individuals described in this paragraph are individuals who--

`(1) are not described in subsection (a)(10)(A)(i);

`(2) have not attained age 65;

`(3) have been screened for breast and cervical cancer under the Centers for Disease Control and Prevention breast and cervical cancer early detection program established under title XV of the Public Health Service Act (42 U.S.C. 300k et seq.) in accordance with the requirements of section 1504 of that Act (42 U.S.C. 300n) and need treatment for breast or cervical cancer; and

`(4) are not otherwise covered under creditable coverage, as defined in section 2701(c) of the Public Health Service Act (45 U.S.C. 300gg(c)).'.

(3) LIMITATION ON BENEFITS- Section 1902(a)(10) of the Social Security Act (42 U.S.C. 1396a(a)(10)) is amended in the matter following subparagraph (F)--

(A) by striking `and (XIII)' and inserting `(XIII)'; and

(B) by inserting `, and (XIV) the medical assistance made available to an individual described in subsection (aa) who is eligible for medical assistance only because of subparagraph (A)(ii)(XV) shall be limited to medical assistance provided during the period in which such an individual requires treatment for breast or cervical cancer' before the semicolon.

(4) CONFORMING AMENDMENTS- Section 1905(a) of the Social Security Act (42 U.S.C. 1396d(a)) is amended in the matter preceding paragraph (1)--

(A) in clause (x), by striking `or' at the end;

(B) in clause (xi), by adding `or' at the end; and

(C) by inserting after clause (xi) the following:

`(xii) individuals described in section 1902(aa),'.

(b) PRESUMPTIVE ELIGIBILITY-

(1) IN GENERAL- Title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) is

amended by inserting after section 1920A the following:

`PRESUMPTIVE ELIGIBILITY FOR CERTAIN BREAST OR CERVICAL CANCER PATIENTS

`SEC. 1920B. (a) STATE OPTION- A State plan approved under section 1902 may provide for making medical assistance available to an individual described in section 1902(aa) (relating to certain breast or cervical cancer patients) during a presumptive eligibility period.

`(b) DEFINITIONS- For purposes of this section:

`(1) PRESUMPTIVE ELIGIBILITY PERIOD- The term `presumptive eligibility period' means, with respect to an individual described in subsection (a), the period that--

`(A) begins with the date on which a qualified entity determines, on the basis of preliminary information, that the individual is described in section 1902(aa); and

`(B) ends with (and includes) the earlier of--

`(i) the day on which a determination is made with respect to the eligibility of such individual for services under the State plan; or

`(ii) in the case of such an individual who does not file an application by the last day of the month following the month during which the entity makes the determination referred to in subparagraph (A), such last day.

`(2) QUALIFIED ENTITY-

`(A) IN GENERAL- Subject to subparagraph (B), the term `qualified entity' means any entity that--

`(i) is eligible for payments under a State plan approved under this title; and

`(ii) is determined by the State agency to be capable of making determinations of the type described in paragraph (1)(A).

`(B) REGULATIONS- The Secretary may issue regulations further limiting those entities that may become qualified entities in order to prevent fraud and abuse and for other reasons.

`(C) RULE OF CONSTRUCTION- Nothing in this paragraph shall be construed as preventing a State from limiting the classes of entities that may become qualified entities, consistent with any limitations imposed under subparagraph (B).

`(c) ADMINISTRATION-

`(1) IN GENERAL- The State agency shall provide qualified entities with--

`(A) such forms as are necessary for an application to be made by an individual described in subsection (a) for medical assistance under the State plan; and

`(B) information on how to assist such individuals in completing and filing such forms.

`(2) NOTIFICATION REQUIREMENTS- A qualified entity that determines under subsection (b)(1)(A) that an individual described in subsection (a) is presumptively eligible for medical assistance under a State plan shall--

`(A) notify the State agency of the determination within 5 working days after the date on which determination is made; and

`(B) inform such individual at the time the determination is made that an application for medical assistance under the State plan is required to be made by not later than the last day of the month following the month during which the determination is made.

`(3) APPLICATION FOR MEDICAL ASSISTANCE- In the case of an individual described in subsection (a) who is determined by a qualified entity to be presumptively eligible for medical assistance under a State plan, the individual shall apply for medical assistance under such plan by not later than the last day of the month following the month during which the determination is made.

`(d) PAYMENT- Notwithstanding any other provision of this title, medical assistance that--

`(1) is furnished to an individual described in subsection (a)--

`(A) during a presumptive eligibility period;

`(B) by a entity that is eligible for payments under the State plan; and

`(2) is included in the care and services covered by the State plan;

shall be treated as medical assistance provided by such plan for purposes of section 1903(a)(5)(B).'

(2) CONFORMING AMENDMENTS-

(A) Section 1902(a)(47) of the Social Security Act (42 U.S.C. 1396a(a)(47)) is amended by inserting before the semicolon at the end the following: 'and provide for making medical assistance available to individuals described in subsection (a) of section 1920B during a presumptive eligibility period in accordance with such section'.

(B) Section 1903(u)(1)(D)(v) of such Act (42 U.S.C. 1396b(u)(1)(D)(v)) is amended--

(i) by striking `or for' and inserting `, for'; and

(ii) by inserting before the period the following: `, or for medical assistance provided to an individual described in subsection (a) of section 1920B during a presumptive eligibility period under such section'.

(c) ENHANCED MATCH- Section 1903(a)(5) of the Social Security Act (42 U.S.C. 1396b(a)(5)) is amended—

(1) by striking `an' and inserting `(A) an';

(2) by adding `plus' after the semicolon; and

(3) by adding at the end the following:

`(B) an amount equal to 75 percent of the sums expended during such quarter which are attributable to the offering, arranging, and furnishing (directly or on a contract basis) of medical assistance to an individual described in section 1902(aa); plus'.

(d) EFFECTIVE DATE- The amendments made by this section apply to medical assistance furnished on or after October 1, 1999, without regard to whether final regulations to carry out such amendments have been promulgated by such date.

END

HR 1070 IH

106th CONGRESS

1st Session

H. R. 1070

To amend title XIX of the Social Security Act to provide medical assistance for certain women screened and found to have breast or cervical cancer under a federally funded screening program.

IN THE HOUSE OF REPRESENTATIVES

March 11, 1999

Mr. LAZIO (for himself, Ms. ESHOO, Ms. ROS-LEHTINEN, Mrs. CAPPS, Mrs. MORELLA, Mrs. KELLY, Mr. BROWN of Ohio, Mr. GEORGE MILLER of California, Mr. HORN, Mr. DIXON, Ms. PELOSI, Mr. LATOURETTE, Mr. WAXMAN, Mr. SERRANO, Mr. GILMAN, Mr. MALONEY of Connecticut, Mr. MEEHAN, Mr. WELDON of Pennsylvania, Mr. UNDERWOOD, Mr. SHOWS, Mr. ABERCROMBIE, Mr. MCHUGH, Mr. ETHERIDGE, Mr. SANDERS, Mrs. CLAYTON, Mr. WALSH, Mr. MCGOVERN, Mr. MCNULTY, Mr. FROST, Mr. NEY, Mr. OLVER, Ms. MILLENDER-MCDONALD, Mr. CROWLEY, Mr. SUNUNU, Mr. CLEMENT, Mr. STARK, Ms. CARSON, Mr. FOLEY, Mr. COYNE, Mr. LANTOS, Mr. INSLEE, Mrs. WILSON, Mr. SHERMAN, Mr. BALDACCI, Mr. BOEHLERT, Mr. LUTHER, Mr. HINOJOSA, Mr. DEFAZIO, Mr. QUINN, Mr. PRICE of North Carolina, Mr. RANGEL, Mr. WEYGAND, Mr. FORBES, Mr. MEEKS of New York, Mr. NADLER, Mr. BARRETT of Wisconsin, Ms. WOOLSEY, Mr. KUCINICH, Mr. KING, Ms. SLAUGHTER, Mrs. TAUSCHER, Mr. BILBRAY, Mr. THOMPSON of Mississippi, Mr. HINCHEY, Mr. KLECZKA, Mr. PAYNE, Mr. WYNN, Mr. JEFFERSON, Mr. SMITH of New Jersey, Mr. MASCARA, Mr. LOBIONDO, Mr. OBERSTAR, Mr. LEACH, Mr. RUSH, Mr. MATSUI, Mr. DINGELL, Mrs. EMERSON, Mr. FILNER, Mrs. MYRICK, and Ms. LOFGREN) introduced the following bill; which was referred to the Committee on Commerce

A BILL

To amend title XIX of the Social Security Act to provide medical assistance for certain women screened and found to have breast or cervical cancer under a federally funded screening program.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. OPTIONAL MEDICAID COVERAGE OF CERTAIN BREAST OR CERVICAL CANCER PATIENTS.

(a) COVERAGE AS OPTIONAL CATEGORICALLY NEEDY GROUP-

(1) **IN GENERAL**- Section 1902(a)(10)(A)(ii) of the Social Security Act (42 U.S.C. 1396a(a)(10)(A)(ii)) is amended--

(A) in subclause (XIII), by striking `or' at the end;

(B) in subclause (XIV), by adding `or' at the end; and

(C) by adding at the end the following:

`~~(XV)~~ who are described in subsection (aa) (relating to certain breast or cervical cancer patients);'.

(2) **GROUP DESCRIBED**- Section 1902 of the Social Security Act (42 U.S.C. 1396a) is amended by adding at the end the following:

`(aa) Individuals described in this paragraph are individuals who--

`(1) are not described in subsection (a)(10)(A)(i);

`(2) have not attained age 65;

`(3) have been screened for breast and cervical cancer under the Centers for Disease Control and Prevention breast and cervical cancer early detection program established under title XV of the Public Health Service Act (42 U.S.C. 300k et seq.) in accordance with the requirements of section 1504 of that Act (42 U.S.C. 300n) and need treatment for breast or cervical cancer; and

`(4) are not otherwise covered under creditable coverage, as defined in section 2701(c) of the Public Health Service Act (45 U.S.C. 300gg(c)).'.

(3) **LIMITATION ON BENEFITS**- Section 1902(a)(10) of the Social Security Act (42 U.S.C. 1396a(a)(10)) is amended in the matter following subparagraph (F)--

(A) by striking `and (XIII)' and inserting `~~(XIII)~~'; and

(B) by inserting `, and (XIV) the medical assistance made available to an individual described in subsection (aa) who is eligible for medical assistance only because of subparagraph (A)(10)(ii)~~(XV)~~ shall be limited to medical assistance provided during the period in which such an individual requires treatment for breast or cervical cancer' before the semicolon.

(4) **CONFORMING AMENDMENTS**- Section 1905(a) of the Social Security Act (42 U.S.C. 1396d(a)) is amended in the matter preceding paragraph (1)--

(A) in clause (x), by striking `or' at the end;

(B) in clause (xi), by adding `or' at the end; and

(C) by inserting after clause (xi) the following:

`(xii) individuals described in section 1902(aa),'

(b) PRESUMPTIVE ELIGIBILITY-

(1) IN GENERAL- Title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) is amended by inserting after section 1920A the following:

`PRESUMPTIVE ELIGIBILITY FOR CERTAIN BREAST OR CERVICAL CANCER PATIENTS

`SEC. 1920B. (a) STATE OPTION- A State plan approved under section 1902 may provide for making medical assistance available to an individual described in section 1902(aa) (relating to certain breast or cervical cancer patients) during a presumptive eligibility period.

`(b) DEFINITIONS- For purposes of this section:

`(1) PRESUMPTIVE ELIGIBILITY PERIOD- The term `presumptive eligibility period' means, with respect to an individual described in subsection (a), the period that--

`(A) begins with the date on which a qualified entity determines, on the basis of preliminary information, that the individual is described in section 1902(aa); and

`(B) ends with (and includes) the earlier of--

`(i) the day on which a determination is made with respect to the eligibility of such individual for services under the State plan; or

`(ii) in the case of such an individual who does not file an application by the last day of the month following the month during which the entity makes the determination referred to in subparagraph (A), such last day.

`(2) QUALIFIED ENTITY-

`(A) IN GENERAL- Subject to subparagraph (B), the term `qualified entity' means any entity that--

`(i) is eligible for payments under a State plan approved under this title; and

`(ii) is determined by the State agency to be capable of making determinations of the type described in paragraph (1)(A).

`(B) REGULATIONS- The Secretary may issue regulations further limiting those entities that may become qualified entities in order to prevent fraud and abuse and for other reasons.

`(C) RULE OF CONSTRUCTION- Nothing in this paragraph shall be construed as preventing a State from limiting the classes of entities that may become qualified entities, consistent with any limitations imposed under subparagraph (B).

`(c) ADMINISTRATION-

`(1) IN GENERAL- The State agency shall provide qualified entities with--

`(A) such forms as are necessary for an application to be made by an individual described in subsection (a) for medical assistance under the State plan; and

`(B) information on how to assist such individuals in completing and filing such forms.

`(2) NOTIFICATION REQUIREMENTS- A qualified entity that determines under subsection (b)(1)(A) that an individual described in subsection (a) is presumptively eligible for medical assistance under a State plan shall--

`(A) notify the State agency of the determination within 5 working days after the date on which determination is made; and

`(B) inform such individual at the time the determination is made that an application for medical assistance under the State plan is required to be made by not later than the last day of the month following the month during which the determination is made.

`(3) APPLICATION FOR MEDICAL ASSISTANCE- In the case of an individual described in subsection (a) who is determined by a qualified entity to be presumptively eligible for medical assistance under a State plan, the individual shall apply for medical assistance under such plan by not later than the last day of the month following the month during which the determination is made.

`(d) PAYMENT- Notwithstanding any other provision of this title, medical assistance that--

`(1) is furnished to an individual described in subsection (a)--

`(A) during a presumptive eligibility period;

`(B) by a entity that is eligible for payments under the State plan; and

`(2) is included in the care and services covered by the State plan;

shall be treated as medical assistance provided by such plan for purposes of section 1903(a)(5) (B).

(2) CONFORMING AMENDMENTS-

(A) Section 1902(a)(47) of the Social Security Act (42 U.S.C. 1396a(a)(47)) is

amended by inserting before the semicolon at the end the following: `and provide for making medical assistance available to individuals described in subsection (a) of section 1920B during a presumptive eligibility period in accordance with such section'.

(B) Section 1903(u)(1)(D)(v) of such Act (42 U.S.C. 1396b(u)(1)(D)(v)) is amended—

(i) by striking `or for' and inserting `, for'; and

(ii) by inserting before the period the following: `, or for medical assistance provided to an individual described in subsection (a) of section 1920B during a presumptive eligibility period under such section'.

(c) ENHANCED MATCH- Section 1903(a)(5) of the Social Security Act (42 U.S.C. 1396b(a)(5)) is amended—

(1) by striking `an' and inserting `(A) an';

(2) by adding `plus' after the semicolon; and

(3) by adding at the end the following:

`(B) an amount equal to 75 percent of the sums expended during such quarter which are attributable to the offering, arranging, and furnishing (directly or on a contract basis) of breast or cervical cancer-related treatment services; plus'.

(d) EFFECTIVE DATE- The amendments made by this section apply to medical assistance furnished on or after October 1, 1999, without regard to whether final regulations to carry out such amendments have been promulgated by such date.

END

Medicaid Breast and Cervical Cancer Treatment Act S. 662**Senate Sponsors**

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164. Rep. Shelley Berkley (D-NV)
165. Rep. James A. Gibbons (R-NV)
166. Rep. Gary L. Ackerman (D-NY)
167. **Rep. Sherwood L. Boehlert (R-NY)**
168. **Rep. Joseph Crowley (D-NY)**
169. Rep. Eliot L. Engel (D-NY)
170. **Rep. Michael P. Forbes (R-NY)**
171. **Rep. Benjamin A. Gilman (R-NY)**
172. **Rep. Maurice Hinchey (D-NY)**
173. Rep. Amo Houghton (R-NY)
174. **Rep. Sue Kelly (R-NY)**
175. **Rep. Peter King (R-NY)**
176. Rep. John J. LaFalce (D-NY)
177. Rep. Nita M. Lowey (D-NY)
178. Rep. Carolyn Maloney (D-NY)
179. Rep. Carolyn McCarthy (D-NY)
180. **Rep. John McHugh (R-NY)**
181. **Rep. Michael R. McNulty (D-NY)**
182. **Rep. Gregory W. Meeks (D-NY)**
183. **Rep. Jerrold Nadler (D-NY)**
184. Rep. Major R. Owens (D-NY)
185. **Rep. Jack Quinn (R-NY)**
186. **Rep. Charles B. Rangel (D-NY)**
187. **Rep. Jose Serrano (D-NY)**
188. **Rep. Louise McIntosh Slaughter (D-NY)**
189. Rep. John E. Sweeney (R-NY)
190. Rep. Edolphus Towns (D-NY)
191. Rep. Nydia Velazquez (D-NY)
192. **Rep. James T. Walsh (R-NY)**
193. Rep. Anthony D. Weiner (D-NY)
194. **Rep. Sherrod Brown (D-OH)**
195. Rep. Paul E. Gillmor (R-OH)
196. Rep. Stephanie Tubbs Jones (D-OH)
197. Rep. Marcy Kaptur (D-OH)
198. **Rep. Dennis J. Kucinich (D-OH)**
199. **Rep. Steven C. LaTourette (R-OH)**
200. **Rep. Robert W. Ney (R-OH)**
201. Rep. Rob Portman (R-OH)
202. Rep. Deborah Pryce (R-OH)
203. Rep. Thomas C. Sawyer (D-OH)
204. Rep. Ted Strickland (D-OH)
205. Rep. J.C. Watts (R-OK)
206. Rep. Earl Blumenauer (D-OR)
207. **Rep. Peter A. DeFazio (D-OR)**
208. Rep. Darlene Hooley (D-OR)
209. Rep. David Wu (D-OR)
210. Rep. Robert A. Borski (D-PA)
211. Rep. Robert A. Brady (D-PA)
212. **Rep. William J. Coyne (D-PA)**
213. Rep. Philip S. English (R-PA)
214. Rep. William F. Goodling (R-PA)
215. Rep. Joseph M. Hoeffel (D-PA)
216. Rep. Ron Klink (D-PA)
217. **Rep. Frank R. Mascara (D-PA)**
218. Rep. John P. Murtha (D-PA)
219. Rep. John E. Peterson (R-PA)
220. **Rep. Curt Weldon (R-PA)**
221. Rep. Patrick J. Kennedy (D-RI)
222. **Rep. Robert A. Weygand (D-RI)**
223. Rep. James Clyburn (D-SC)
224. **Rep. Bob Clement (D-TN)**
225. Rep. Harold Ford (D-TN)
226. Rep. Bart Gordon (D-TN)
227. Rep. William Jenkins (R-TN)
228. Rep. Joe Barton (R-TX)
229. Rep. Kenneth E. Bentsen (D-TX)
230. Rep. Henry Bonilla (R-TX)
231. Rep. Chet Edwards (D-TX)
232. **Rep. Martin D. Frost (D-TX)**
233. Rep. Charles A. Gonzalez (D-TX)
234. Rep. Gene Green (D-TX)
235. Rep. Ralph M. Hall (D-TX)
236. **Rep. Ruben E. Hinojosa (D-TX)**
237. Rep. Sheila Jackson-Lee (D-TX)
238. Rep. Eddie Bernice Johnson (D-TX)
239. Rep. Nick Lampson (D-TX)
240. Rep. Ciro D. Rodriguez (D-TX)

- 241. Rep. Max A. Sandlin (D-TX)
- 242. Rep. Merrill Cook (R-UT)
- 243. Rep. Rick Boucher (D-VA)
- 244. Rep. James P. Moran (D-VA)
- 245. Rep. Frank R. Wolf (R-VA)
- 246. Rep. Donna Christian-Green (D-VI)
- 247. **Rep. Bernard Sanders (I-VT)**
- 248. Rep. Brian Baird (D-WA)
- 249. Rep. Norman D. Dicks (D-WA)
- 250. Rep. Jennifer Dunn (R-WA)
- 251. **Rep. Jay Robert Inslee (D-WA)**
- 252. Rep. James A. McDermott (D-WA)
- 253. Rep. Jack Metcalf (R-WA)
- 254. Rep. Adam Smith (D-WA)
- 255. Rep. Tammy Baldwin (D-WI)
- 256. **Rep. Tom Barrett (D-WI)**
- 257. Rep. Ron J. Kind (D-WI)
- 258. **Rep. Gerald D. Kleczka (D-WI)**
- 259. Rep. Thomas E. Petri (R-WI)
- 260. **Rep. Nick Joe Rahall (D-WV)**

The Breast and Cervical Cancer Treatment Act of 1999
S. 662/H.R. 1070
Endorsing Organizations

National Breast Cancer Coalition
American Cancer Society
American Association of Public Hospitals & Health Systems
National Partnership for Women & Families
YWCA
National Women's Health Network
Oncology Nursing Society
Y-ME
Arm in Arm
Association of Women's Health, Obstetric, and Neonatal Nurses
Rhode Island Breast Cancer Coalition
Florida Breast Cancer Coalition
The Breast Cancer Coalition of Utah
Maine Breast Cancer Coalition
American Medical Women's Association
American Public Health Association
California Breast Cancer Organizations
Linda Creed Breast Cancer Foundation
Wisconsin Breast Cancer Coalition
Cancer Research Foundation of America
American Society for Therapeutic Radiology and Oncology

TABLE 1

**National Breast and Cervical Cancer Early Detection Program (NBCCEDP)
Initiation of Treatment for Women Diagnosed with In Situ or Invasive Breast Cancer
Minimum Data Elements¹ through March 31, 1997**

Program Name	Total Number of NBCCEDP Funded Mammograms	Total Number of Breast Cancers Diagnosed (In Situ/Invasive) ²	Number of Breast Cancers with Complete Information	Median Days from Diagnosis to Treatment Initiation	Percent Initiated Treatment (N=) ³	Number of Breast Cancers with Pending/Missing Information ⁴
TOTAL for NBCCEDP (35 Programs Combined) ⁵	594,436	4409	4242	10	95.8 (4064)	167

¹ The Minimum Data Elements (MDEs) are electronically submitted semi-annually (January 15 and July 15) to a data management contractor, who analyzes the data and submits a data file to the CDC. For example, the data used for this report were submitted on January 15, 1998 and included screening exams through September 30, 1997. The next data will be submitted on July 15, 1998 and will include screening exams through March 31, 1998. The interval of three and one-half months provides states time to prepare the data submission and gather information that may be missing. Routinely an additional six month interval is provided for completion of diagnostic follow-up and treatment information.

² The total number of breast cancers diagnosed include some women referred to the NBCCEDP for diagnostic evaluation of a non-NBCCEDP funded screening exam.

³ Women who did not initiate treatment either refused treatment, were lost to follow-up, or died.

⁴ Breast cancer cases have pending or missing information on one or more of the following variables: date of diagnosis; date of treatment initiation; or status of treatment initiation.

⁵ Programs include AK, AZ, AR, CA, CO, CT, FL, GA, IL, IA, KS, LA, ME, MD, MA, MI, MN, MO, NE, NJ, NM, NY, NC, OH, OK, OR, PA, RI, SC, TX, UT, VT, WA, WV, WI

TABLE 2

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)
Initiation of Treatment for Women Diagnosed with In Situ or Invasive Breast Cancer
Minimum Data Elements through March 31, 1997
Program with ≥ 40 Cases of Breast Cancer

Program Name	Total Number of NBCCEDP Funded Mammograms	Total Number of Breast Cancers Diagnosed (In Situ/Invasive)	Number of Breast Cancers with Complete Information	Median Days from Diagnosis to Treatment Initiation	Percent Initiated Treatment (N=)	Number of Breast Cancers with Pending/Missing Information
AR	5,652	54	52	10	96.1 (50)	2
CA	50,767	489	478	11	93.1 (445)	11
CO	20,485	119	117	13	99.1 (116)	2
MD	35,788	314	305	11	96.7 (295)	9
MA	14,038	207	182	13	97.3 (177)	25
MI	58,473	435	424	0	94.3 (400)	11
MN	26,375	217	215	8	97.7 (210)	2
MO	24,041	143	140	8	96.4 (135)	3
NE	2,950	79	78	8	91.0 (71)	1
NM	47,613	244	244	18.5	95.9 (234)	0
NY	59,573	397	397	25	94.2 (374)	0
NC	42,191	274	269	11	94.0 (253)	5
OH	10,254	121	121	8	95.9 (116)	0
PA	5,593	48	43	13	100 (43)	5

5/5/98

TABLE 2 (continued)

**National Breast and Cervical Cancer Early Detection Program (NBCCEDP)
Initiation of Treatment for Women Diagnosed with In Situ or Invasive Breast Cancer
Minimum Data Elements through March 31, 1997
Program with ≥ 40 Cases of Breast Cancer**

Program Name	Total Number of NBCCEDP Funded Mammograms	Total Number of Breast Cancers Diagnosed (In Situ/Invasive)	Number of Breast Cancers with Complete Information	Median Days from Diagnosis to Treatment Initiation	Percent Initiated Treatment (N=)	Number of Breast Cancers with Pending/Missing Information
SC	30,192	227	206	10	98.5 (203)	21
TX	71,662	526	514	4.5	97.9 (503)	12
UT	5,918	43	41	0	100 (41)	2
WA	12,812	71	61	8	90.2 (55)	10
WV	32,063	214	198	7	99.5 (197)	16
WI	10,860	40	36	10.5	97.2 (35)	4

TABLE 3

**National Breast and Cervical Cancer Early Detection Program (NBCCEDP)
Initiation of Treatment for Women Diagnosed with In Situ or Invasive Breast Cancer
Minimum Data Elements through March 31, 1997
Program with < 40 Cases of Breast Cancer**

Program Name	Total Number of NBCCEDP Funded Mammograms	Total Number of Breast Cancers Diagnosed (In Situ/Invasive)
AK	989	8
AZ	1,495	13
CT	1,302	8
FL	1,535	14
GA	6,234	31
IL	1,102	6
IA	416	5
KS	785	7
LA	174	1
ME	872	3
NJ	2,549	11
OK	1,328	15
OR	1,115	11
RI	1,269	7
VT	979	7

NOTE: Median days from diagnosis to treatment initiation and the proportion who have initiated treatment are not calculated because the total number of breast cancer cases are too small to produce statistically reliable information. However, those breast cancer cases are included in the overall NBCCEDP measures reported in Table 1. These states are still in the start-up stage and have been screening for approximately two years as of March 31, 1997.

Mammography or Mammography Referral

sliding scale	200% FPL	250% FPL	other
Florida	Alabama	Alaska	Mississippi (150% FPL)
Kentucky (up to 250% FPL)	Arizona	CNMI	Nebraska (no information)
	Arkansas	Delaware	New Mexico (185% FPL)
	California	D.C.	
	Colorado	Hawaii	
	Connecticut	Indiana	
	Georgia	Maryland	
	Idaho	Massachusetts	
	Illinois	Michigan	
	Iowa	Minnesota	
	Kansas	New Jersey	
	Louisiana	New York	
	Maine	Oregon	
	Missouri	Pennsylvania	
	Montana	Rhode Island	
	Nevada	South Carolina	
	New Hampshire	Utah	
	North Carolina		
	North Dakota		
	Ohio		
	Oklahoma		
	Repub. of Palau		
	South Dakota		
	Tennessee		
	Texas		
	Vermont		
	Virgin Islands		
	Virginia		
	Washington		
	West Virginia		
	Wisconsin		
	Wyoming		

Congress of the United States

Washington, DC 20515

July 21, 1999

The Honorable Thomas J. Bliley
Chairman
Committee on Commerce
2125 RHOB
Washington, D.C. 20515

Dear Chairman Bliley:

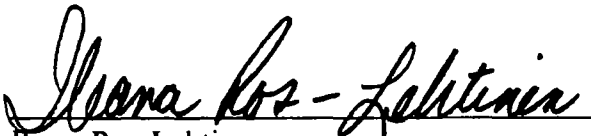
We are writing to urge you to bring H.R. 1070, the Breast and Cervical Cancer Treatment Act, to the floor this session. This bipartisan bill, which currently has over 260 cosponsors in the House of Representatives, would give states the option of providing Medicaid coverage for treatment of low-income women diagnosed with breast cancer through the federal Centers for Disease Control and Prevention's (CDC) Breast and Cervical Cancer Early Detection Program.

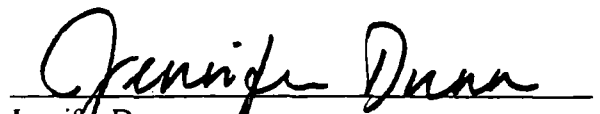
In 1990, Congress established the CDC Early Detection Program to reduce the rate of death from breast cancer. However, we need to remember that breast cancer screening alone does not prevent breast cancer deaths; it must be coupled with treatment if we are to achieve a reduction in mortality. The best way to ensure that happens is to enact H.R. 1070, the Breast and Cervical Cancer Treatment Act, into law as soon as possible. Women's lives depend on it!

We, the Republican women in Congress, believe that if we care enough about women's health to provide coverage for screenings, then we should care enough to provide treatment when these screenings find cancer. H.R. 1070 would help ensure that our mothers, daughters and sisters receive the help they need at one of the most vulnerable time in their lives.

Thank you for your assistance.

Sincerely,


Heana Ros-Lehtinen


Jennifer Dunn


Mary Bono


Connie Morella


Sue Myrick


Heather Wilson


Sue Kelly


Jo Ann Emerson

Marge Roukema
Marge Roukema

* Uncorrected
version

Breast Cancer:
A Report on the Fight to
Prevent, Treat, and Cure the Disease



THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

OCT 20 1993

MEMORANDUM FOR THE PRESIDENT

Marking National Breast Cancer Awareness Month, I am pleased to present to you *Breast Cancer: A Report on the Fight to Prevent, Cure, and Treat the Disease*

In these last five years, we have seen great strides toward the eradication of breast cancer. In 1993, at your request, I convened the Conference to Establish the National Action Plan on Breast Cancer (NAPBC). The NAPBC, a public-private partnership, serves as a catalyst for national efforts in six priorities areas identified through the conference, including biological resources, breast cancer etiology, hereditary susceptibility, clinical trials, information dissemination and consumer involvement. I also convened the Federal Coordinating Committee on Breast Cancer in 1994. The FCCBC, a liaison group to the NAPBC, fosters collaboration and cooperation in cross-cutting initiatives and reduces unnecessary duplication of effort in breast cancer programs.

As you read this report, I hope you will be pleased at the breadth of breast cancer activities across the Administration. While we have achieved much, we must recognize the work that lies ahead. Thank you for your continued leadership and commitment to this public health priority.

A handwritten signature in black ink, appearing to read "D. Shalala", is centered below the text.

Donna E. Shalala

Attachment

Breast Cancer:
A Report on the Fight to
Prevent, Treat, and Cure the Disease

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Breast Cancer: A Report on the Fight to Prevent, Treat, and Cure the Disease

Thirty years ago, people only whispered the words breast cancer, and a diagnosis of breast cancer meant a virtual death sentence. Today, breast cancer is at the forefront of the nation's health care agenda, and we have made tremendous strides to prevent, detect, and treat the disease. Since 1993, the Clinton Administration has been committed to waging this battle on numerous fronts. First, the Administration has made a significant investment in research--reaching over \$500 million in 1998. Second, we have improved the quality and availability of early detection tools like mammography. Third, we have worked to improve access to treatment and quality of care for women with breast cancer. The Administration has fostered cooperation and communication among the government, experts, survivors, and advocates, primarily through the National Action Plan on Breast Cancer, a public-private partnership. The Administration has also worked to increase collaboration among government agencies through the Federal Coordinating Committee on Breast Cancer.

Breast cancer mortality rates have improved markedly in the United States, declining 4.6 percent between 1991 and 1995 alone. However, breast cancer remains the second leading cause of cancer deaths among American women. Today, one in eight women will develop breast cancer, up from one in 20 just two decades ago. In 1998, approximately 180,000 new cases of breast cancer will be diagnosed and the disease will claim nearly half a million lives in this decade.

Faced with these still daunting statistics, the Administration has made a tremendous investment in breast cancer research, prevention, and treatment. In FY1998 alone, the Clinton Administration invested almost \$700 million in the fight against breast cancer. The Department of Health and Human Services, which includes research by the National Institutes of Health (NIH) and screening through Centers for Disease Control (CDC), has nearly doubled its discretionary spending on breast cancer from \$283 million in FY1993 to an estimated \$550 million today. Additionally, the Department of Defense's Breast Cancer Research Program spent \$135 million in FY1998 on innovative peer-reviewed breast cancer research. The Clinton Administration has also expanded its investment in breast cancer through the Medicaid and Medicare programs which provide mammograms and breast cancer treatment to countless women.

In recent years, intensive research has yielded important breakthroughs. A 1994 study revealed two genes that increase a woman's risk of developing breast cancer, and President Clinton has announced \$30 million of additional funding to explore further the role of genes in breast cancer susceptibility. This year, tamoxifen was shown to reduce the incidence of breast cancer by 49 percent in women at high risk for the disease. The Food and Drug Administration (FDA) has recently approved new detection and treatment devices, and is putting drugs for women with breast cancer on a fast track for approval. Drugs recently approved by the FDA include Herceptin, a drug that may help slow the progress of the disease once it has spread to other parts

of the body, and Taxol, a drug that when used with chemotherapy helps patients whose cancer has reached the lymph nodes. And more ground breaking research is ongoing, including studies of environmental factors contributing to breast cancer; the NIH's Women's Health Initiative, which is examining opportunities to reduce breast cancer through diet; and the Cancer Anatomy Genome Project, which since its launch in 1997 has already identified more than 300,000 DNA sequences and 12,000 new genes in an effort to understand better the genetics of breast cancer -- double what the National Cancer Institutes (NCI) originally anticipated.

The Administration has also worked to educate women about and improve access to mammography and other tools of early detection. This year, due to the President's leadership, Medicare began covering annual mammograms for all beneficiaries age 40 and over and made them more affordable by waiving the deductible. On October 9, the President signed the reauthorization of the Mammography Quality Standards Act, under which the FDA sets high standards to ensure that mammograms are safe and accurate and certifies those facilities that meet its standards. The Clinton Administration has also spearheaded a number of outreach initiatives and programs to ensure that women have access to mammograms. The First Lady launched a campaign in 1995 to encourage older women to take advantage of the mammography benefit offered by Medicare, and this campaign continues each year with the support of the Health Care Financing Administration and numerous private partners. This year's effort focuses on improving mammography rates among minority women. CDC's National Breast and Cervical Cancer Early Detection Program offers free or low-cost mammograms to uninsured, low-income, elderly, and minority women.

The Administration has also fought tirelessly to improve access to treatment and quality of health care for women with breast cancer. The President has fought to prevent health plans and employers from discriminating against individuals based on their genetic information, so that advances in genetic research can be used to help detect breast cancer rather than to discriminate. He has also urged Congress to pass a patients' bill of rights that will guarantee critical protections to patients with breast cancer -- including access to specialists and a fair appeals process. To help breast cancer patients participate in clinical trials, last month the President directed NCI to implement a new system that will make it easier for physicians to enroll patients in clinical trials. The Administration has also urged Congress to pass legislation that would allow Medicare to cover patient care costs for cancer clinical trials. To address racial disparities in treatment, access to care, and health status, the Administration has proposed an initiative to address health disparities in six major areas, including cancer. And finally, building on unprecedented efforts begun at the Department of Defense and the FDA, next year NCI will fully integrate patients and advocates into policy planning and grant reviews. With each of these advances we are moving closer to discovering the cure for breast cancer.

Significant challenges remain. We must continue to fight for legislation ending discrimination against individuals based on their genetic information. We must continue to fight for strong, enforceable patients' bill of rights legislation. We must continue to increase access to clinical trials. We must continue to work to end racial disparities that still exist in breast cancer

mortality, mammography rates, and access to treatment. We must continue to integrate advocates in planning the cancer research agenda. And, most important, we must continue to support research that builds on the dramatic research breakthroughs we have seen in recent days to find a cure, and finally an end, for breast cancer.

OVERVIEW

Background

Breast cancer is the most commonly diagnosed cancer, excluding skin cancer, and the second leading cause of cancer deaths among American women. There is no proven way yet to lower the risk for breast cancer, so early detection through mammography and clinical breast exams is essential.

In 1998, approximately 180,000 new cases of breast cancer will be diagnosed, and about 43,500 women are expected to die from breast cancer. Epidemiological studies estimate that breast cancer will be diagnosed in 1.5 million American women in this decade and that breast cancer will claim nearly half a million lives.

While the lifetime risk of developing breast cancer today is one in every eight women, up from one in every 20 women just two decades ago, this rate increase can be substantially attributed to improved detection of the disease.

Declining Mortality Rates

Mortality rates have steadily declined for most women. With early detection and proper treatment, the chances of surviving breast cancer are improving. Death rates from the disease remain highest among older, African-American, and low-income women. During the most recent 5-year period, death rates among white women declined for all decades of ages from 30 to 79 years. Among black women, rates were down for all decades of ages from 30 to 69 years. Among both groups, the greatest improvements in mortality were seen in the younger age groups or women ages 30 to 39 years, rates dropped about 13 percent among whites and 5 percent among blacks. For women ages 40 to 49 years, rates dropped 9 percent among whites and 2 percent among blacks.

A study in the medical journal *Cancer* (July 1998) attributes the decrease or leveling off in breast cancer mortality to a trend toward progressively earlier diagnosis of cancer which is more treatable than later stage cancers. According to this study, the number of patients diagnosed with the earliest stages of the disease increased from 42 percent in 1985 to 46 percent in 1995. For women ages 50 to 69, to having regular mammograms can reduce the chance of death from breast cancer by one-third or more. Despite these numbers, 33 percent of women ages 50 to 64, and 45 percent of women age 65 and older reported not having had a mammogram during the past two years.

Increased Funding

The Clinton Administration is committed to fighting the threat posed by the disease on many fronts with investments in research, outreach and education.

Because cancer research is vital to understanding how to prevent, detect, and treat breast cancer. The Clinton Administration has dramatically increased investments in breast cancer research. The Department of Health and Human Services (DHHS) discretionary funding for breast cancer has nearly doubled in the years since 1993 from approximately \$283 million in FY 1993 to nearly \$550 million today. At the National Institutes of Health (NIH) alone funding increased from \$237 million in FY1993 to an estimated \$433 million in FY1998.

As the Centers for Disease Control and Prevention (CDC) have worked to increase access for all women to mammography screening and follow up services, its resources devoted to breast cancer services have increased from an estimated \$43 million in FY 1993 to \$85 million in FY 1998. The Department of Health and Human Services also helps provide access to treatment for breast cancer through the Medicare and Medicaid programs and the Indian Health Service.

The Department of Defense (DoD) will invest \$135 million in FY1999 for innovative, peer reviewed breast cancer research.

In addition, President Clinton directed \$30 million in new funding for research into the genetic basis of breast cancer, through a collaborative initiative between the Department of Defense (DOD) and the Department of Health and Human Services in October 1996. This collaboration utilizes the Department of Defense's and the National Cancer Institute's breast cancer research programs to explore further the genetic basis of breast cancer and the most effective methods of treating those genetically predisposed to the disease.

Finally, this past summer, the U.S. Postal Service issued a breast cancer research stamp, valid for the 32 cent first-class rate but selling for 40 cents. The additional 8 cents (minus U.S. Postal Service costs) will be donated to breast cancer research, with 70 percent of the proceeds going to National Institutes of Health and 30 percent to the Department of Defense's medical research program.

SCIENTIFIC PROGRESS IN THE FIGHT AGAINST BREAST CANCER

In recent years, intensive research into all aspects of breast cancer has led to a flurry of important new discoveries. Scientists understand now more than ever before how a healthy breast cell becomes cancerous, how breast cancer spreads, and why some tumors are more aggressive than others. Indeed, we are witnessing not only advances in treatment and detection, but for the first time, serious advances in prevention of breast cancer. These discoveries are leading to more refined technologies for detecting and diagnosing breast cancer, to better care and improved outcomes for patients during and after treatment, and ultimately, to prevention of the disease completely.

The Administration's increased efforts against this deadly disease have yielded promising results. At the forefront of the battle to fight breast cancer are the National Cancer Institute at the National Institutes of Health, which leads the nation's efforts in cancer research, and the Food and Drug Administration, which reviews and approves cancer drugs and devices while maintaining safe standards. Additionally, interagency collaborations continue on scientific research regarding other potential risk factors for breast cancer, including high-fat diet, hormonal therapies and environmental toxins.

The Administration has made a critical commitment to improve research by integrating advocates in planning and setting the cancer research agenda. Over the past six years, the breast cancer program at the Department of Defense has grown into one of the most renowned research programs in the nation. This unprecedented partnership between the military, scientists, physicians, and the community to fund grants to invigorate breast cancer research actively involves breast cancer survivors in defining this program and sitting on the scientific panel review boards. The Food and Drug Modernization Act of 1997 also included new efforts to integrate patients and advocates in setting the research agenda. Finally, the National Cancer Institute has also made new efforts to integrate patients and advocates. In fact, last month the President and Vice President announced that, by next year, NCI will fully integrate patients and advocates into a wide range of critical activities such as reviewing grant proposals and planning policy.

Advances in Prevention

Prevention of breast cancer is the overall goal of scientific research. A breakthrough achievement this year showed that breast cancer can be prevented for some women at high risk for the disease. Studies in cancer genetics are also providing unprecedented insight into the development and evolution of cancer and are generating knowledge about the most basic processes involved in the onset of breast cancer -- those at the molecular level.

New Drugs Approved that will Save Lives. A true medical breakthrough has been the discovery of a breast cancer prevention agent -- Tamoxifen -- earlier this year. This drug has been shown

to reduce the incidence of breast cancer by 49 percent in women at high risk for the disease. Its discovery was a product of the *Breast Cancer Prevention Trial*, a national clinical trial, sponsored by the National Cancer Institute. This clinical trial proved for the first time that it is possible to reduce the short term incidence of breast cancer in women at greater than average risk of breast cancer. In September 1998, a Food and Drug Administration advisory committee recommended Tamoxifen reduce incidence of breast cancer in high risk women. The NCI is now developing an education program to help physicians and patients decide who should consider taking tamoxifen.

Identifying New Markers for Breast Cancer. A 1994 study on women with a history of breast cancer revealed two different breast cancer susceptibility genes, BRCA1 and BRCA2, which increase a woman's risk for developing breast cancer. This study was conducted by the National Institute for Environmental Health Sciences in conjunction with the University of Utah and Myriad Genetics. Scientists have found that alterations in these two important genes are associated with most inherited breast cancers. While only 5 to 10 percent of all breast cancers are the result of an inherited anomaly, these findings hold promise for development of new prevention, early detection and treatment strategies. Women who choose to be tested for these genes, once tested, may be able to take preventive steps in consultation with their physicians to reduce the chances that they will succumb to the disease.

In October 1996, President Clinton announced \$30 million in funding for a new research initiative which will focus on a broad range of investigations related to the role of genes in the development of breast cancer. This collaborative effort between the Department of Defense and the National Institutes of Health may enable high-risk women to prevent breast cancer before it strikes.

Current Clinical Trials which will Lead to Prevention Breakthroughs. The National Heart, Lung and Blood Institute is leading a consortium of NIH institutes engaged in the Women's Health Initiative (WHI). The initiative includes one of the largest set of clinical trials ever conducted on the causes and prevention of breast cancer. The trial is studying the relationship between diet and the disease in a clinical trial of over 49,000 women, which may lead to information that women can use in order to deter the onset of breast cancer. The observational study of over 92,000 women will be looking for new risk factors, including genetic factors, for breast cancer. The major results of the Women's Health Initiatives are expected after 2005.

Advances in Treatment

Over the last five years, there have been incredible advances in treatment of breast cancer, which given more women with the disease a chance to fight it. Indeed, it is in part due to these recent advances in treatment that death rates for this disease are dropping. New treatment approaches are evolving, including the sequencing of chemotherapies, the development of monoclonal antibodies shown to boost the immune systems to fight cancer growth, new drugs for advanced breast cancer, and medications to help prevent the disease from occurring.

FDA's Fast Track for Review and Approval of Cancer Drugs. Since 1996, the Food and Drug Administration (FDA) has accelerated the review and approval of new drugs and has improved the therapy review process by ensuring that all FDA cancer-therapy advisory committee meetings include an *ad hoc* member who has personal experience with the illness for which a new product is being considered.

FDA's Initiatives on Reinventing of Cancer Drugs. On March 26, 1996, President Clinton announced the Food and Drug Administration (FDA)'s Initiatives on Reinventing of Cancer Drugs outlining several initiatives to enhance cancer drug development and to provide opportunities for cancer patients to be actively involved in the FDA's cancer drug advisory committee process. The President's initiative enhanced FDA's strong commitment to both rapid and thorough evaluation of therapies for serious and life-threatening diseases.

Recently approved drugs that will provide women with advanced breast cancer options for treatment are Herceptin, Zoladex (gosereline acetate implant), Arimidex (anastrozole), Taxotere (docetaxel), Xeloda (capecitabine), Femara (letrozole), Fareston (toremifene citrate), and Aredia (pamidronate disodium).

Herceptin. On September 25, 1998, FDA approved Herceptin, the first genetically-engineered antibody therapy for patients with metastatic breast cancer. Developed by a biotechnology firm working with the National Cancer Institute, Herceptin is a monoclonal antibody, one of a group of drugs designed to attack specific cancer cells that produce a protein called HER2 or HER2/neu. Studies indicate that Herceptin can help 25 to 30 percent of patients with advanced breast cancer.

Taxol. Early findings of a large, NCI multi-center trial show that the drug Taxol, when used in combination with other standard chemotherapy agents, has a small but significant benefit for breast cancer patients whose disease has spread to nearby lymph nodes. Although the survival advantage is small at this point in the trial, the study is considered important because it is the first to show that Taxol may be beneficial in the initial, post-surgical treatment of some women with localized, node positive breast cancer.

Study of Tamoxifen and Raloxifene (STAR Trial). The NCI will sponsor another large-scale study in early 1999 to compare five years of tamoxifen to five years of raloxifene for the prevention of invasive breast cancer in high-risk women. Nearly 200 institutions across the United States are expected to participate in the study of 22,000 post-menopausal women over age 35.

Environmental Factors and Breast Cancer. In August 1994, the DHHS Public Health Service's Office on Women's Health established a Federal Interagency Coordinating Committee on the Environment and Women's Health that focuses on how home, work, atmospheric pollutants, exogenous hormones, drugs, and other environmental factors may contribute to the risk of breast cancer and other disorders. Studies supported by the NCI and National Institute for

Environmental Health Sciences (NIEHS) are currently underway on the role of the environment in cancer risk in the northeast and mid-Atlantic portions of the U.S. These studies are testing the risk from organochlorine compounds, PCBs, and estrogen-like chemicals, such as DDT, DDE, and other pesticides. To date, there does not seem to be increased risk of breast cancer from these chemicals overall. However, there are some groups of women who may be more susceptible to the effects of DDT. For example, women who never breast-fed and some women who have certain genetic alterations may be at increased risk if exposed to these chemicals. Likewise, some forms of PCBs (called congeners) may be more estrogenic, making them possible risk factors for breast cancer. Studies are needed on exposures during a woman's childhood or adolescence, when she is more vulnerable to chemical exposures.

NASA Technology. NASA uses the microgravity of space to grow human tissue for research and transplantation and to gain valuable knowledge important to the treatment of breast and ovarian cancer. The NASA-designed Bioreactor is a unique tissue culture chamber that grows cells in three-dimensions. These tissues, similar to tissues found in the body, will help scientists understand cancer growth and how the human immune system responds.

Advances in Detection

As scientists work on the cure for this disease that strikes so many women, the Clinton Administration is also investing in the research needed to find better detection methods for breast cancer. As we know, early detection is the key to survival with breast cancer, and therefore, these new research methods are saving lives.

FDA's New Frontiers. The Food and Drug Administration (FDA) has recently approved several different types of devices for the detection and treatment of breast cancer including:

- Serum tumor markers (CA15-3 and CA27-29) used to monitor breast cancer patients' responses to therapy and the recurrence of the disease;
- Assays to measure HER2/neu protein in breast cancer tissues;
- An ultrasound system (Advanced Technology Labs HDI 3000) to be used in conjunction with mammography to help differentiate benign from malignant or suspicious lesions; and,
- A computer-based system (R2 Technology Model M1000 Image Checker) that identifies regions of interest on routine screening mammograms to bring them to the attention of the radiologist after the initial reading has been completed.

The Cancer Genome Anatomy Project (CGAP). Launched in 1997, the CGAP is working to identify the genetic differences among normal, precancerous, and cancerous cells. This project

will help foster the discovery of genes that are directly expressed in cancer. These can be used to identify early precancerous cells, and thus enhance early detection methods. The CGAP initiative will also aid in the ability to match individual patients with the most appropriate treatments. Although this project is designed to collect data for all cancers, researchers are initially concentrating on five major cancers, including breast cancer.

The project has already identified more than 300,000 DNA sequences and 12,000 new genes -- double what the NCI initially expected. The Administration is committed to ensure that progress in understanding the genetics of cancer is used to develop new innovative techniques to detect and treat cancer. That is why last month, the President and Vice President issued a historic challenge to scientists to use the CGAP to develop new diagnostic techniques in the next two years for every major cancer.

NASA's technology. Collaborations with NASA and its investigations into the mysteries of the universe have resulted in technology to better detect breast cancer. Some of the highlights include:

- Silicon chips used in the Hubble Space Telescope were adapted so doctors can easily detect tiny spots in breast tissue and analyze the tissue using a needle rather than subject a patient to painful surgery. This procedure also eliminates scarring or disfigurement, requires half the time of traditional techniques, reduces exposure to x-rays, and reduces costs from \$3500 to \$850.
- Mars Pathfinder technology developed to enhance pictures is being modified to make three-dimensional models of breast tissue. Combining ultrasound with advanced computing, the imaging device discerns cancerous from healthy tissue by comparing changes in shape and analyzing the ultrasound signal. This enables doctors to differentiate tissue more accurately without using painful invasive procedures.

Breast Cancer Surveillance Consortium. Established in October 1994 by NCI, the Breast Cancer Surveillance Consortium is comprised of nine academic and public institutions and private organizations. The consortium's three main objectives are:

- To better understand breast cancer screening practices in the United States by assessing the accuracy, cost, and quality of screening programs and the relation of these practices to changes in breast cancer mortality and other outcomes, such as survival;
- To foster collaborative research among Consortium participants that examines issues such as regional and health care system differences in the provision of screening and follow-up evaluations; and
- To provide a foundation for conducting clinical and basic science research, especially basic

research on biological mechanisms, that can improve our understanding of the natural history of breast cancer.

By the year 2000, it is estimated that the Consortium's database, with data collected from nine participating sites across the country, will contain information on nearly 3.2 million mammograms and over 24,000 cases of breast cancer. The data will enable researchers to compare mammography screening practices among different regions of the country.

Further Research Steps to a Cure

Current clinical trials now underway will provide much needed data on the optimal adjuvant treatment for node positive breast cancer patients. One of these trials should finish recruiting patients soon, and early findings could be available in the next one or two years. Another clinical trial using Taxotere, a drug similar to Taxol, in the treatment of node positive patients is still open to patients.

Marking Progress

In September 1998, NCI's Breast Cancer Progress Review Group examined progress in the eight major areas of breast cancer research, as well as broad research directions and infrastructure needs of breast cancer research. The Group made the following recommendations to continue and accelerate the prevention, detection, diagnosis and treatment of this disease:

- Enhanced understanding of normal breast biology and genetics;
- Better model systems for premalignant and malignant breast disease;
- Fuller understanding of molecular changes through the continuum of breast cancer progression;
- Identification of biomarkers and surrogate endpoints for epidemiologic, prevention, and therapy trials;
- Ensured investigator access to necessary technology;
- Enhanced infrastructure at academic health centers;
- Modifications of existing mechanisms to promote translational, prevention, and therapy trials;
- Improved communications efforts and more patient-focused outcome;
- Research in basic behavioral change, decision making, and communication;
- Recruitment, training, and retention of translational investigators;
- Enhanced communication among investigators in various disciplines;
- Reassessment of funding strategies to target innovation and accommodate longitudinal studies; and,
- Streamlined consent process for clinical research.

Other Federal Research Activities

Department of Defense Breast Cancer Research Program. The United States Army Medical Research and Materiel Command has been responsible for administering targeted appropriations for breast cancer, prostate cancer, ovarian cancer, neurofibromatosis, and osteoporosis. In Fiscal Year 1992 the Breast Cancer Research Program (BCRP) was established, funded at \$25 million for breast cancer research. Since 1993, the program's funding has increased steadily to \$135 million to further breast cancer research.

In 1995, in response to Congressional directives, 21 special mammography projects were funded through the BRCF. Fiscal Year 1996 saw a change in the type of research awards offered. The program supported Idea awards and Clinical Translational Research awards. These new award categories provided support for research that was not offered by other agencies, such as the National Cancer Institute. In Fiscal Year 1997, in response to Congressional directives, \$6 million was earmarked for computer-based decision support systems and \$2.3 million for research on calcium signaling/cancer cell proliferation. Finally, in 1998, consistent with previous programs, the Breast Cancer Research Program continued to encourage a unique, broad-based research agenda, attracting talented new as well as established investigators to the field of breast cancer.

Environmental Protection Agency. The Environmental Protection Agency's Office of Prevention, Pesticides, and Toxic Substances is leading the charge on research into the emerging issue of endocrine disruptors and their link to breast cancer. Pesticides, toxic substances, and other forms of pollution can interfere with and mimic the body's natural estrogen, a now agent in breast cancer etiology.

COMMITMENTS TO EARLY DETECTION OF BREAST CANCER

The Clinton Administration has worked to educate and to improve access to mammography screening among all women, particularly older women and minority populations.

New Mammography Benefits. Proposed by President Clinton and adopted under the Balanced Budget Act of 1997, Medicare expanded its coverage of several preventative procedures, including mammograms, on January 1, 1998. The expanded benefits include coverage to help pay for annual screening mammograms for all Medicare beneficiaries age 40 and over. Under the expanded benefits, Medicare waives the Part B deductible for screening mammograms, providing women ages 65 and older greater access to this important benefit. In addition to mammography, the Balanced Budget Act also expanded a variety of preventative benefits for women, including pap smears, colorectal screening, bone mass measurement, and flu and pneumococcal shots.

Mammography Awareness Campaign Aimed at Older Americans. Committed to educating older women about the importance of detecting breast cancer early, First Lady Hillary Rodham Clinton launched a mammography awareness campaign in 1995. Aimed at women 65 and older, the campaign urges older women who are less likely than younger women to get mammograms, to have annual mammograms and promotes the use of Medicare coverage for mammogram screenings. As part of this ongoing education campaign, President Clinton and the First Lady have appeared in television public service announcements encouraging older women to get annual mammogram screenings.

Mammography Quality Standards Act (MQSA). On October 9, 1998, President Clinton signed the reauthorization of the Mammography Quality Standards Act. The Act gives the FDA the authority to set high standards for mammography facilities and certifies those which meet the standards. The estimated 10,000 mammography facilities nationwide certified by the FDA must meet quality standards for equipment, personnel, quality assurance, and record keeping, and are inspected annually.

MQSA regulations require facilities to hire capable technologists, use quality dedicated equipment that produces clear images, and employ skilled physicians to interpret the results both accurately and efficiently. The rules also require that doctors and patients be fully and quickly informed of results so that necessary follow-up testing or treatment can begin.

The FDA has included a list of all FDA certified mammography facilities in the United States on its Internet home page, <http://www.fda.gov/cdrh/faclist.html>, and this list is available by calling the NCI's Cancer Information Service at 1-800-4-CANCER.

Mammography for Underserved Americans. The Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) offers free or low-cost mammography screening to uninsured, low-income, elderly, and minority women nationwide. These underserved populations tend to have the highest breast cancer death rates.

The program, which now encompasses all fifty states, five territories, the District of Columbia, and fifteen American Indian/Alaska Native organizations, has provided over 1.7 million screening tests to more than 1.2 million medically underserved women since its inception. The NBCCEDP is able to screen 12-15 percent of the eligible population for these cancers.

HORIZON Grants to Improve Mammography Rates Among Minority Women. The Health Care Financing Administration has included a new focus to improve its mammography rates among minority Medicare beneficiaries. HCFA launched the Horizon Project grants, a three-year initiative in six major cities (Atlanta, Chicago, Cleveland, Los Angeles, Philadelphia, and San Antonio) which focuses efforts on increasing mammography rates among Hispanic and African-American Medicare beneficiaries. These comprehensive efforts will not only encourage more women in these areas to get regular mammograms but provide insight on how to overcome barriers that prevent women from getting mammograms, such as language barriers and misconceptions that only women of childbearing are at risk for breast cancer.

HCFA has partnered with the Washington, D.C. ABC-TV affiliate and Safeway Food Stores on two PSAs that aired in May, 1998. Building on the success of this Mother's Day campaign, HCFA is broadcasting a series of 30-second TV ads for National Breast Cancer Awareness Month in October, 1998. These spots will air in five of the six multi-city mammography sites -- Atlanta, Philadelphia, Chicago, Cleveland, Los Angeles and D.C. The PSAs are geared to African-American Medicare beneficiaries, a population at particular risk.

Mammography for Women with Addictive and Mental Disorders. Women who are in need of or receive substance abuse or mental health services often lack appropriate primary health care, including breast cancer education, screening, and treatment. Women-focused substance abuse and mental health programs, funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), are designed to be comprehensive and to deliver primary health care services to women, many of whom are medically underserved. These services include education on breast self-examination, mammography services, and counseling on risks for breast cancer.

Mobile Digital Telemammography Breast Cancer Center. Inter-departmental collaborations are also underway for developing a Mobile Breast Care Center that will generate and transmit a patient's digital mammogram via satellite to a breast screening center, where a radiologist will interpret the images and relay any need for additional evaluation back to the mobile unit. The Mobile Breast Care Center will benefit medically underserved populations, particularly women living in rural and remote areas.

QUALITY OF CARE AND ACCESS TO TREATMENT

Improving Access and Increasing Participation in Clinical Trials. The Administration has made unprecedented efforts in helping breast cancer patients participate in clinical trials. Currently, only 3 percent of cancer patients participate in cancer clinical trials. Many scientists believe that higher participation in clinical trials could lead to faster development of therapies for more of those in need, as it often takes between 3 and 5 years to enroll enough participants in a cancer clinical trial to make the results scientifically legitimate and statistically meaningful. Also, cure rates for many childhood cancers are approaching 80 percent, in part because almost all children with cancer are either enrolled in clinical trials or treated according to protocols developed through clinical trials.

To increase participation in clinical trials, last month the President directed NCI to fully implement a new system to make it easier for physicians to enroll patients in clinical trials. Under the directive, NCI will complete this simplified system for breast, colon and prostate cancers by next spring and expedite the system for other cancers as well. This new system will ensure that physicians are informed about cutting-edge cancer clinical trials and will allow them to enroll patients on the spot. This effort will give tens of thousands of cancer patients improved access to cancer clinical trials.

The Administration has also asked Congress to pass legislation that would allow coverage of cancer clinical trials for Medicare beneficiaries. Americans over the age of 65 make up half of all cancer patients, and are 10 times more likely to get cancer than younger Americans. Older Americans, however, frequently cannot participate in cutting-edge cancer clinical trials because Medicare does not pay for experimental treatments. This legislation would give older Americans access to cutting edge treatments.

Eliminating Racial and Health Disparities. The President has also proposed a comprehensive race and health initiative designed to eliminate racial health disparities in six critical health areas, including cancer. This effort includes \$450 million over five years to test innovative approaches. To learn more about that includes a grant program for new community-based approaches to address disparities. Successful approaches identified in these projects will be applied throughout all new programs and initiatives at the Department of Health and Human Services. The President has also proposed \$300 million to build on successful programs that have proven effective at addressing these disparities, including the breast cancer screening and treatment program at the Indian Health Service.

Office of Cancer Survivorship. On October 27, 1996, President Clinton unveiled the new Office of Cancer Survivorship at the National Cancer Institute. Recent success of cancer prevention, early detection, and treatment efforts has created a new need: research into the physical, psychological, and economic well-being of the growing number of cancer survivors. There now are more than 8 million cancer survivors of which about 2 million American women are breast

cancer survivors. The Office of Cancer Survivorship will support research covering the range of issues facing survivors of cancer, including: long term medical and psychological effects, factors that predispose survivors of cancer, second malignancies, reproductive problems following cancer treatment, and their unique insurance and employment issues. In August 1998, NCI committed \$15 million over the next five years to cancer survivorship grants that will be overseen by this office. These grants support top-of-the-line research on issues faced by long-term cancer survivors.

Cancer Information Service (CIS). In its 26th year, the National Cancer Institute's Cancer Information Service is a national information and education network, providing the latest, most accurate cancer information for patients, the public, and health professionals. Approximately 25 percent of all CIS calls are related to breast cancer. Specifically, trained staff provide the latest scientific information in understandable language, and will offer the location of the caller's nearest FDA certified mammography facility. With staff available to answer questions in English and Spanish, the CIS responds to about 600,000 phone calls annually through its toll-free number (1-800-4CANCER).

Ensuring Rights for Breast Cancer Patients. The Clinton Administration has urged Congress to pass a strong, enforceable Patients' Bill of Rights to protect the rights of all health care consumers and their families and to assure that the health care system is fair and responsive to consumers' needs. Among the patient protections proposed by the President's Advisory Commission last year, there are special protections for breast cancer patients: guaranteed access to specialists, which would allow cancer patients to have direct access to their oncologists without having to see a primary care physician for a referral; and transitional care, which would allow patients to continue with an oncologist for a period of time, even if their insurance changes or if the doctor leaves or is terminated from a managed care plan. President Clinton has already taken steps to apply these patient protections to all federal health care programs and plans that serve 85 million Americans, including Medicare, Medicaid, and the Federal Employees Health Benefits program.

Privacy of Genetic Information and Breast Cancer. President Clinton has also supported bipartisan legislation to prohibit health plans from inappropriately using genetic screening information to deny coverage or to set premiums. The Administration has also asked Congress to pass legislation that prevents employers from discriminating on the basis of genetic information. In many diseases, such as breast cancer, scientists are beginning to identify genetic alterations that may place a woman at increased risk. Women who test positive may increase cancer detection efforts, may elect to have preventive surgery, or may join a cancer prevention research study. However, genetic information may be used by insurance companies and others to discriminate and stigmatize individuals and groups of people. In fact, studies show that one of the leading reasons women do not get genetic testing for breast cancer is because they fear the information will be used to discriminate against them.

Access to Important Medical Procedures. The Congress has just passed and the President will soon sign into law, new protections to assure that women whose health plan covers mastectomies also cover breast reconstructive surgery for those women who chose it.

The President has also endorsed bipartisan legislation that ensures that women are not forced out of the hospital before they are ready because of pressure from their health plan. DHHS also sent a letter to all Medicare managed care plans making it clear that they may not set time limits for inpatient hospital treatment or requirements for outpatient treatment, and that rather a woman and her doctor should make decisions about what is medically necessary.

Department of Veterans Affairs. Department of Veterans Affairs (VA) is an active partner with many other federal, state, and local organizations to meet the health care needs of women veterans. The VA is also one of the largest breast health service providers in our nation.

NEW APPROACHES IN ADDRESSING THE DISEASE

The Administration has responded by forming unprecedented collaborations within the federal government and forging public-private partnerships to reach all communities, particularly populations that are underserved.

National Action Plan on Breast Cancer

Under President Clinton's direction and under the leadership of DHHS Secretary Donna Shalala, the National Action Plan on Breast Cancer (NAPBC) was developed in 1993 to spearhead the national response to breast cancer and foster cooperation and communication with experts inside and outside government. The NAPBC is co-chaired by Wanda K. Jones, Dr.P.H., Deputy Assistant Secretary for Health (Women's Health) and Fran Visco, Esq., President of the National Breast Cancer Coalition.

The plan has identified the following six priority areas: biological resources, etiology, hereditary susceptibility, clinical trials, consumer involvement and information dissemination. Six working groups were formed to identify and implement specific initiatives within these priority areas. Through its six working groups, the NAPBC has played a pivotal role in catalyzing national efforts, including activities of governmental and non-governmental organizations, agencies, and individuals in the fight against breast cancer.

Accomplishments of the NAPBC include:

Building Partnerships: One-Time Grants. In September 1995, the NAPBC awarded over \$9 million in one-time grants for 99 innovative research and outreach projects, with a special emphasis on the development of public-private partnerships targeted in the six original priority areas. These grants focused on the broad topic areas with the NAPBC working groups including, biological resources, etiology, hereditary susceptibility, public education, clinical trials and consumer involvement.

Raising Awareness about Health Insurance and Workplace Discrimination. The NAPBC played a pivotal role raising awareness on the basis of an individual's genetic predisposition to disease by developing recommendations for federal and state policies. Both sets of recommendations were published in the medical journal *Science* in October 1995 and March 1997 respectively. The Administration has developed a set of principles based on these recommendations and, in the summer of 1997, the President called upon Congress to pass legislation that would prohibit discrimination against individuals predisposed to the disease.

Linking Women to Breast Cancer Information. In October 1996, President Clinton launched the NAPBC Internet Web site (<http://www.napbc.org>). The web site serves as a gateway to information on breast cancer research, prevention, detection, and treatment. The number of hits on this site was last reported to average around 40,000 hits per month.

The NAPBC web site provides answers on frequently asked questions about breast cancer, as well as information on the NAPBC, breast cancer clinical trials and research, breast cancer organizations and advocacy groups, educational conferences, publications, and government and private resources.

Bridging the Gap Initiative Pilot Project. A pilot project designed and implemented in which five community-based organizations across the nation are finding innovative ways to link informationally-underserved women with breast cancer information through new technology such as the Internet and WebTV. The five existing sites included Bowling Green, Kentucky; Boston, Massachusetts; Little Rock, Arkansas; San Francisco, California; and Anchorage, Alaska.

Involving Consumers. A survey was conducted to assess the extent of consumer involvement in activities in areas such as breast cancer research, service delivery, education and outreach, and public policy. The ultimate goal is to identify and implement ways to bridge the gaps between the current status and potential status of consumer involvement.

Overcoming Barriers to Participation in Clinical Trials. An extensive literature search was conducted to reveal barriers to participation in clinical trials and identify potential means of reducing those barriers. This information is now being analyzed and will be compiled into a critical review of the literature that will be submitted for publication early next year.

Developing "Hereditary Susceptibility to Breast and Ovarian Cancer: An Outline of Fundamental Knowledge Needed by All Health Care Professionals." This outline serves as a framework for high-quality, customized education and training for health care professionals on the implications of genetic testing for breast cancer susceptibility.

Developing "Genetic Testing for Breast Cancer Risk: It's Your Choice." This video was developed and over 30,000 copies were distributed to medical practitioners, cancer centers and breast cancer organizations. The video addresses the pros and cons as well as psychosocial issues involved in genetic testing to assist consumers in making informed choices about genetic testing.

Developed a Breast Cancer Comprehensive Questionnaire. This questionnaire was developed and focus-group tested in order to understand the causes of this disease. Six etiologic areas -- addressing environmental exposures, sociodemographic factors, occupational exposures, medical history, lifestyle, and diet -- and long and short versions of a core questionnaire provide a standardized set of questions, for use by all researchers on risk factors linked to breast cancer.

Publishing. Papers were published on "Hormones, Hormone Metabolism, Environment, and Breast Cancer" in a supplement to the journal, *Environmental Health Perspectives*, in April 1997.

Publishing Proceedings. Three papers summarizing the November 1997 “Workshop on Physical Activity and Breast Cancer” were published in a supplement to the medical journal, *Cancer*, on August 1, 1998.

Conducting Focus Groups. Telephone focus groups were conducted in the Fall 1997 in order to design a plan for a marketing campaign, intended to demystify breast cancer clinical trials, promote awareness, and encourage women to learn about and enroll in such trials. The design of a plan for the marketing plan is expected to be completed in early 1999, at which time partner organizations will be sought to implement its components.

Advancing Research. Through public and private partners, a network of tissue banks was designed and implemented to assist researchers needing biological materials for breast and other cancer research studies. This network can be accessed through the NAPBC Web site.

Creating Guidelines. Guidelines were developed for Institutional Review Boards (IRBs) and others. A model patient consent form, and a patient fact sheet on donating tissue samples for research were also produced.

Federal Coordinating Committee on Breast Cancer

Under the Clinton Administration, all federal agencies have mobilized and joined in the battle against breast cancer through establishment of the Federal Coordinating Committee on Breast Cancer (FCCBC). The FCCBC was formed at the direction of the Secretary in response to the Secretary’s 1993 Conference on Breast Cancer as a liaison group to the National Action Plan on Breast Cancer. It is comprised of representatives from all DHHS agencies, and other departments across the federal government including the Department of Defense, Department of State, Veterans Affairs, Environmental Protection Agency, Department of Labor, and the Department of Housing and Urban Development. The group fosters focuses attention on the disease across agencies, collaboration and cooperation in crosscutting initiatives, and reduces unnecessary duplication of efforts. The FCCBC has developed an Internet-accessible inventory of all government breast cancer activities.

FCCBC Supplement Grant Program. In September 1997, the FCCBC provided supplemental funding for a diverse portfolio of grants that increase knowledge of the causes of breast cancer, improve early detection, prevention and treatment of the disease, and bring lifesaving outreach and education programs to many medically underserved women across the nation.

The program awarded \$2.7 million to fund 22 innovative projects, with 50 percent of funding directed to programs which address the needs of underserved populations. Emphasizing interagency collaborations, the Supplemental Grant Program’s highlights include:

- A research project supported by the Agency for Health Care Policy and Research to better

understand the frequency of “drive-through” mastectomies in the era of managed care.

- An Indian Health Service project to expand the training and support of community health aides in the delivery of breast cancer early detection services to Alaska Native women in rural Alaskan villages.
- A project supported by the Health Resources and Services Administration to expand breast cancer services to Hispanic farm workers.
- A research project conducted by the National Institute of Environmental Health Sciences that will provide the foundation for a novel approach to identifying environmental chemicals with the potential to cause breast cancer.
- A National Cancer Institute project that is collecting in-depth survey information to evaluate the impact of a no-cost cancer screening program for low income, African-American women.
- The development of a database sponsored by the Health Care Financing Administration to measure the impact of breast cancer screening interventions for Hispanic Medicare beneficiaries.
- A Centers for Disease Control and Prevention research study to investigate a common variation of the protein p53, which appears to be a susceptibility factor for breast cancer. The study defines the link between this variant and different environmental and occupational exposures. The study may assist in determining why breast cancer in African-Americans and Hispanics often differs from Caucasians.
- A study by the Food and Drug Administration to reduce toxicity and improve the effectiveness of a chemotherapy drug, amino glutethimide, and a standard treatment of choice for cancer patients who no longer respond to tamoxifen.
- A Department of Agriculture outreach project to underserved women in Northern Appalachia to educate them about breast health and the possible preventative benefits of proper nutrition.
- A Department of Energy project to develop imaging technology to validate positive mammograms and thereby help reduce unnecessary biopsies.

FCCBC Partnering Workshop. In September 1998, the FCCBC convened a workshop entitled “Partnering to Improve Outcomes: Opportunities for Collaboration in Government Breast Cancer Programs.” The workshop highlighted federal activities related to breast cancer and encouraged the formation of new partnerships while strengthening existing interagency collaborations in breast cancer research, policy, services, and public health. The closing session

of the workshop outlined barriers to and facilitators of federal partnerships throughout the conference.

Other Collaborations

Federal Multi-Agency Consortium on Imaging to Improve Women's Health. In July 1994, the Public Health Service's Office on Women's Health, in collaboration with NCI, began an initiative to examine technologies currently under exploration for improving breast imaging. The Federal Multi-Agency Consortium on Imaging to Improve Women's Health is exploring the applications of technologies from other fields to improve the early detection and diagnosis of illnesses and conditions affecting women.

The Department of Health and Human Services has been working with the Department of Defense, the Central Intelligence Agency, National Aeronautics and Space Agency, and other public and private entities to enhance the ability to detect breast cancer at its earliest stages and to explore opportunities in telemedicine.

In particular, the computer technologies that have been used to improve spy satellites may help improve breast cancer detection and treatment at its earliest stages. In October 1996, DHHS awarded \$1.98 million to the University of Pennsylvania to conduct a series of clinical trials of imaging technology from the intelligence community—originally used for missile guidance and target recognition—to improve the early detection of breast cancer.

In October 1996, the Food and Drug Administration (FDA) sponsored a conference "The Transfer of Defense, Intelligence, Space and Energy Technologies to the Early Detection and Control of Cancers in Women," in an effort to facilitate such public/private partnerships.

National Mammography Campaign. The Health Care Financing Administration and the National Cancer Institute have entered into an inter-agency agreement to develop, implement, and promote a short term joint health promotion campaign targeting Medicare beneficiaries. The purpose of the campaign is to increase awareness of the importance of the expanded Medicare benefit and regularly scheduled mammography screening among women ages 65 and older.

As part of the agreement, NCI has developed mammography publications to target older women. The new publications include a poster and bookmark featuring an older woman and the Medicare message, as well as a large-print, easy-to-read brochure. All materials will include information on Medicare's expanded benefit and will be printed in English and Spanish.

Centers for Disease Control and Prevention's Public/Private Partnerships. Partnerships are critical to the CDC's cancer control efforts. A successful national program to control breast and cervical cancers, such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), depends on the involvement of a variety of committed partners and national organizations. CDC collaborates with state and local governments, health care professionals and

organizations, social service and voluntary organizations, and academia.

Through these critical partnerships, CDC assists private and public nonprofit organizations in the following program areas:

- Developing, implementing, and evaluating national and community-based interventions for cancer prevention and early detection;
- Testing new methods and replicating proven strategies to educate their constituents about breast and cervical cancers; and,
- Increasing access to breast and cervical cancer screening among underserved women.

CDC and Partners Helping Underserved Women. In October 1993, a unique public-private partnership was established among CDC, Avon Products Inc., the YWCA of the U.S.A., the National Alliance of Breast Cancer Organizations (NABCO), and the National Cancer Institute. The partnership seeks to educate women about breast health and to improve access to early detection services. Avon's Breast Cancer Awareness Crusade has raised more than \$25 million for breast cancer programs nationwide through the sale of its Breast Cancer Awareness pink ribbon products.

Since 1993, about 300 community-based programs in 49 states and Puerto Rico have received funding, from Avon's Crusade through the YWCA of the U.S.A. and NABCO, to educate women about breast cancer and to provide underserved women with access to early detection services. Earlier this year, all funding of community-based programs was consolidated under the Breast Health Access Fund administered by NABCO.

CDC and Partners Assisting At-Risk Populations. Partnerships that focus their prevention efforts on those at greater risk are essential for understanding and alleviating the disparities that exist. Deaths due to breast cancer are decreasing among white women, but not as steadily among African-American women. Both mammography and Pap tests are underutilized by women who are members of racial and ethnic minority groups, have less than a high school education, are older, or live below the poverty level.

To address these differences in the burden of cancer and in the use of cancer prevention services, CDC funds a strong and effective network of partners that are well-positioned in the communities at risk including:

- The U.S. Conference of Mayors' Research and Education Foundation
- The National Center for Farmworkers Health, Inc.
- The American Social Health Association
- The Association of Asian Pacific Community Health Organizations
- The National Hispanic Council on Aging
- The Baylor College of Medicine "Salud en Accion Program"
- The Institute for the Advancement of Social Work Research

- The Mautner Project for Lesbians with Cancer
- The National Asian Women's Health Organization
- The National Association of Community Health Centers
- The National Education Association Health Information Network
- The National Caucus and Center on Black Aged, Inc.
- The Witness Project
- The World Education

These partners have developed projects that focus on specific at-risk populations and cover a wide range of prevention and research activities. For example, many projects are involved with developing low literacy, bilingual, and culturally appropriate educational campaigns. These prevention techniques and research efforts result in increasing knowledge and awareness of breast and/or cervical cancer and promoting screening for early detection in communities around the nation.

CHALLENGES AND NEW FRONTIERS

While continuing to work toward the ultimate goal of eradicating breast cancer, the Clinton Administration is striving to meet new challenges in its ongoing campaign against this deadly disease:

1. We must ensure adequate and sustained support for research. Only research can unlock tomorrow's medical discoveries and treatments.
2. We can only defeat breast cancer if researchers and scientists continue to work together, across agency lines, departmental walls, and the public-private divide.
3. We must work to increase participation in cancer clinical trials to assure that breast cancer patients have access to cutting-edge research and to help speed up discoveries.
4. We must continue to work to ensure that advances and breakthroughs translate into high quality care for breast cancer patients. We have heard too many stories about breast cancer patients who could not see the needed specialist or who had critical treatment denied or delayed until it was too late. We must work to enact protections that breast cancer patients need and deserve.
5. As we crack the genetic code, it should be used to improve treatment, not increase discrimination. No person should have their health care or their job put at risk because they are genetically at risk for cancer.
6. We must continue efforts to expedite new cutting edge treatments for breast cancer, while maintaining our commitment to quality and public health.
7. We must renew our scientific efforts to discover the cause of racial disparities in breast cancer rates between white women and women of color in order to close the gaps. This will help ensure that all women, regardless of race or ethnicity, benefit from our progress against breast cancer.
8. We must to improve early detection so that more women catch breast cancer at its earliest and most treatable stages.
9. We must learn more about the environmental factors that cause breast cancer; and
10. We must find ways to send young women clear messages about the importance of a healthy lifestyle to prevent breast cancer, and other diseases, before they start.

To address the devastating disease of breast cancer in the new millennium will require that we strengthen our partnerships across the government and within the private sector to move forward an agenda that will eventually lead to the eradication of this devastating disease. In the first six months of 1999 we will join together consumers, policymakers, researchers and advocacy organizations for a day of dialogue on breast cancer. We will reflect upon all that has been accomplished to conquer this disease over the past five years, including progress that has been made in breast cancer research, policies, services, and health outcomes, and chart the course for addressing the disease over the next five years.