Cancer Action Network℠
American Cancer Society®

DECADES *of* DETECTION

Progress and Challenges of the National Breast and Cervical Cancer Screening and Treatment Programs

This year marks a historic time in the decades-long fight to turn our nation's "sick care" system into one that focuses on helping people stay well and get well. The enactment of meaningful health care reform in March represents a major step forward in achieving the American Cancer Society's (the Society) and American Cancer Society Cancer Action Network's (ACS CAN) goal of improving access to health care nationwide.

As the chief executive officer of the Society and ACS CAN, and the president of ACS CAN respectively, we have heard thousands of disheartening stories from people who do not have access to preventive services and treatments due to the lack of adequate, affordable health insurance. The Patient Protection and Affordable Care Act has the potential to ensure that more Americans have access to lifesaving tests, such as mammograms and Pap tests, without the cost burden of co-pays or deductibles.

The promise of prevention will only be fulfilled through effective implementation of the new law. If we succeed in transforming our fragmented health care system, we will help save lives from cancer while producing a healthier and more productive population.

To help elevate prevention, we must build on what works and repair what doesn't. Programs, such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which predates the Affordable Care Act, have proven to be successful in reducing the unequal burden of cancer among low-income and medically underserved women.

The NBCCEDP brings breast and cervical cancer screenings and post-screening diagnostic services to low-income, uninsured, and underinsured women. Unfortunately, the program is grossly underfunded, and thus is unable to serve all eligible women. In fact, the program serves fewer than one in five eligible women nationwide.

NBCCEDP is, unquestionably, one of the most effective and lifesaving cancer control programs supported by the Centers for Disease Control and Prevention (CDC). As the nation works to implement the Affordable Care Act, the NBCCEDP will continue to play a critical safety-net role, especially in minority and underserved communities. Rather than dial back NBCCEDP, now is the time to strengthen the program to ensure that it reaches its full potential.

This report serves as a guide on what we know is working with the program and what we need to do to best serve women through the NBCCEDP. The blueprint for action details the need for collaboration and affirms that improvement is possible. We need to ensure that we work together to protect the health and well-being of the nation's most vulnerable populations.

John R. Seffrin, PhD
Chief Executive Officer
American Cancer Society and
American Cancer Society
Cancer Action Network

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President
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MISSION

The American Cancer Society

The American Cancer Society is the nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.

The Society's national headquarters is located in Atlanta, Georgia, and its 12 Divisions nationwide carry out the Society's mission at the state and local level.

The American Cancer Society Cancer Action Network

ACS CAN, the nonprofit, nonpartisan advocacy affiliate headquartered in Washington, D.C., supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN works to encourage elected officials and candidates to make cancer a top national priority. ACS CAN gives ordinary people extraordinary power to fight cancer with the training and tools they need to make their voices heard.

INTRODUCTION

This year, it is estimated that 207,000 women in the United States will be diagnosed with breast cancer and another 40,000 will die from the disease. Furthermore, an estimated 12,000 women will be diagnosed with cervical cancer, and another 4,000 will die from it.

Many of these deaths could be avoided if breast and cervical cancer screening rates increased among women nationwide. Screening mammography can reduce breast cancer mortality rates as much as 30 percent, saving thousands of lives each year.[1] Further reductions in breast cancer death rates are possible by increasing mammography screening rates and providing timely access to high-quality follow-up and treatment. Even more striking, cervical cancer screenings using the Pap test can actually prevent cancer altogether by detecting precancerous lesions.

The Society has strongly promoted routine screening for cervical cancer with the Pap test for the past 50 years and has recommended routine mammography screening since the 1980s.

Cervical cancer incidence and mortality rates have decreased 70 percent over the past three decades. Most of the reduction has been attributed to the Pap test, which finds changes in the cervix before they become cancers. With the recent Food and Drug Administration (FDA) approval of vaccine immunization against human papillomavirus (HPV) among young girls, there is a great potential for further reducing the occurrence of cervical cancer in the United States.

Increasing use of preventive and early detection services is one of the greatest opportunities to reduce the burden of breast and cervical cancer. Unfortunately, many women do not have access to these lifesaving tests. For uninsured or underinsured women, only 26 percent over the age of 40 had a mammogram in the past year, compared with 56 percent of adequately insured women.

In addition, the economic downturn is straining family finances and prompting more Americans to forgo preventive care and visits to the doctor. A survey conducted by ACS CAN found that nearly one-third of Americans with household incomes of less than $35,000 have put off potentially lifesaving cancer screenings, such as mammograms.

The need to protect women's access to preventive health services and to provide access to breast and cervical cancer screenings is greater than ever. This report highlights the impact of the NBCCEDP, which was signed into law 20 years ago. This successful national program has brought lifesaving breast and cervical cancer screening, information, and access to follow-up treatment and services to medically underserved women – especially poor, low-income, racial and ethnic minorities – who would otherwise have gone without.

Decades of Detection celebrates the program from its beginnings in the early 1990s to what is today. The report salutes the women who are served by the program, its champions and supporters, as well as the everyday heroes dedicated to providing quality cancer care to women in need. It also provides a call to action to increase support for this grossly underfunded program, which is a critical part of our nation's health care system.

As cancer advocates, ACS CAN has the responsibility to educate the public about how to prevent and fight cancer effectively. This requires that federal, state and local policy-makers take action. That is why ACS CAN joins the Society in urging legislators and advocates to use this report to help fight back against breast and cervical cancer and saves lives.

BASIC FACTS ABOUT BREAST AND CERVICAL CANCER[1]

What is breast cancer?

Breast cancer is a disease in which malignant (cancer) cells form in the tissues of the breast. There are many different types of breast cancer, with different stages (spread), aggressiveness and genetic makeup; survival varies greatly, depending on those factors. Breast cancer is the most common cancer among women in the United States, other than skin cancer. It is the second leading cause of cancer death in women, after lung cancer.

The following are the most recent estimates by the American Cancer Society for female breast cancer in the United States for 2010:

- 207,090 new cases of invasive breast cancer
- 39,840 deaths from breast cancer

Is there a test that can find breast cancer early?

Mammograms are the best tests for finding breast cancer early. Mammograms are a series of x-rays of the breast that allow doctors to look for early signs of breast cancer, sometimes up to three years before it can be felt during an examination. When breast cancer is found early, treatment is most effective, and many women go on to live long and healthy lives.

When should I get a mammogram?

Most women should have their first mammogram at age 40 and then have another mammogram annually. If you have any symptoms or changes in your breast, or if breast cancer runs in your family, talk to your health care professional. He or she may recommend that you have mammograms earlier or more often.

What is cervical cancer?

When cancer starts in the cervix, it is called cervical cancer. The cervix is the lower, narrow end of the uterus. Also known as the womb, the uterus is where a baby grows when a woman is pregnant. The cervix connects the lower part of the uterus to the vagina (birth canal).

HPV, a common virus that can be passed from one person to another during sexual intercourse, is the main cause of cervical cancer and also causes many vaginal and vulvar cancers. At least half of sexually active people will have HPV at some point in their lives, but only a small percentage of women with HPV will get cervical cancer.

The following are the most recent estimates by the American Cancer Society for cancer of the cervix in the United States for 2010:

- 12,200 new cases of invasive cervical cancer (cancer that has spread beyond the cervix)
- 4,210 deaths from cervical cancer

Cervical cancer is highly preventable in most Western countries because screening tests and a vaccine to prevent HPV infections are available. When cervical cancer is found early, it is highly treatable and associated with long survival and good quality of life.

Is there a test that can prevent cervical cancer?

Yes. Most cervical cancer can be prevented. There are two ways to prevent this disease. The first is to find and treat pre-cancers before they become cancer, and the second is to prevent the pre-cancers.

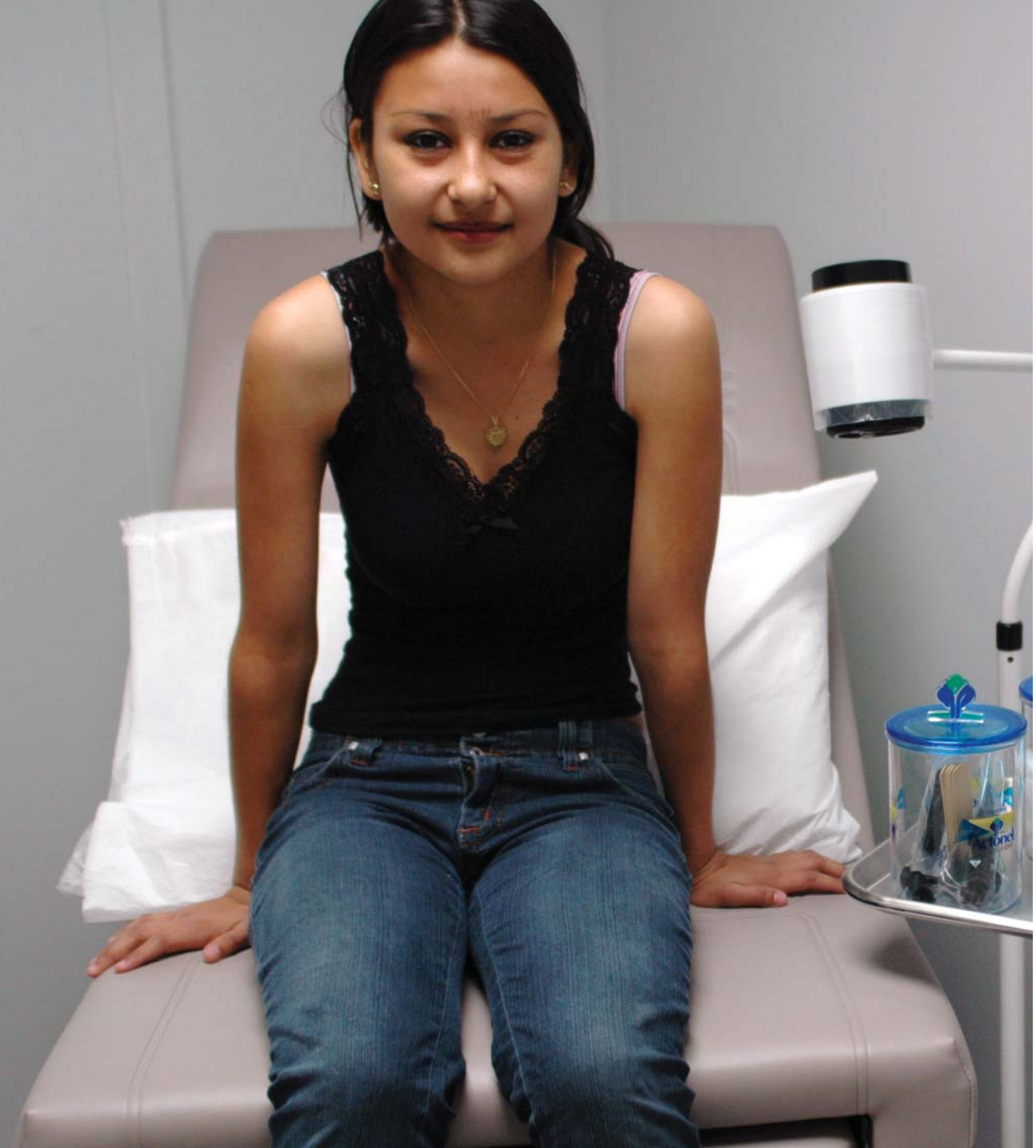
A well-proven way to prevent cancer of the cervix is to have testing (screening) to find pre-cancers before they can turn into cancer. The Pap test (or Pap smear) is the most common way to do this. If a pre-cancer is found and treated, it can stop cervical cancer before it really starts. Most invasive cervical cancers are found in women who have not had regular Pap tests.

The Pap test is a simple procedure in which a small sample of cells is collected from the cervix and examined under a microscope. Pap tests are effective but not perfect. Their results sometimes appear normal even when a woman has abnormal cells of the cervix, and likewise, sometimes appear abnormal when there are no abnormal lesions on the cervix. DNA tests to detect HPV strains associated with cervical cancer may be used in conjunction with the Pap test, particularly when results are equivocal. Fortunately, most cervical pre-cancers develop slowly, so nearly all cases can be prevented if a woman is screened regularly.

There are now also vaccines that prevent the two types of genital HPV, which cause 70 percent of cervical cancer and genital warts. The vaccines, Gardasil and Cervarix, are given in three shots within six months. The vaccine is routinely recommended for 11- and 12-year-old girls. It is also recommended for girls and women older than 13 who have not yet been vaccinated or completed the vaccine series. The FDA has approved both vaccines for females ages nine to 26; clinical trials for using the vaccine in males are currently under way.

When should I get a Pap test?

All women should begin cervical cancer testing (screening) about three years after they start having sex (vaginal intercourse). A woman who waits until she is 18 or older to have sex should start screening no later than age 21. A regular Pap test should be done every year. If a liquid-based Pap test is used instead, women should be tested every two years.



Who Should Get the HPV Vaccine?

To be most effective, one of the HPV vaccines should be given before a female has any type of sexual contact with another person. Both are given in a series of three doses within six months.

The American Cancer Society makes the following recommendations for each age group:

- Girls ages 11 to 12: The vaccine should be given to girls in this age group, and as early as age 9.
- Girls ages 13 to 18: Girls in this age group who have not yet started the vaccine series, or who have started but have not completed the series, should be vaccinated.
- Young women ages 19 to 26: Some authorities recommend vaccination of women in this age group, but the American Cancer Society believes that there is not enough evidence of benefit to recommend vaccinating all women in this age group. The Society does recommend that women ages 19 to 26 talk to their doctors or nurses about whether to get the vaccine based on their risk of previous HPV exposure and potential benefit from the vaccine.

THE AMERICAN CANCER SOCIETY BREAST AND CERVICAL CANCER SCREENING GUIDELINES

Breast Cancer

- Yearly mammograms are recommended starting at age 40 and continuing for as long as a woman is in good health.
- A clinical breast exam (CBE) is recommended about every three years for women in their 20s and 30s and every year for women 40 and over.
- Women should know how their breasts normally look and feel and report any breast change promptly to their health care provider. Breast self-exam (BSE) is an option for women starting in their 20s.

The American Cancer Society recommends that some women – because of their family history, a genetic tendency or certain other factors – be screened with MRI in addition to mammograms. The number of women who fall into this category is small; less than two percent of all the women in the United States. Women should talk with their doctor about their family history and whether they should have additional tests at an earlier age.

Cervical Cancer

- All women should begin cervical cancer screening about three years after they begin having vaginal intercourse, but no later than 21 years of age. Screening should be done every year with conventional Pap tests, or every two years using liquid-based Pap tests.
- Beginning at age 30, women who have three normal Pap test results in a row may get screened every two to three years. Women older than 30 may also get screened every three years with either the conventional or liquid-based Pap test, plus the HPV test.
- Women 70 years of age or older, who have had three or more normal Pap tests in a row and no abnormal Pap test results in the past 10 years, may choose to stop having cervical cancer screenings.
- Women who have had a total hysterectomy (removal of the uterus and cervix) may also choose to stop having Pap tests, unless the surgery was done as a treatment for cervical cancer or pre-cancer. Women who have had a hysterectomy without removal of the cervix should continue to have Pap tests.

Because of their history, some women may need to have a different screening schedule for cervical cancer.

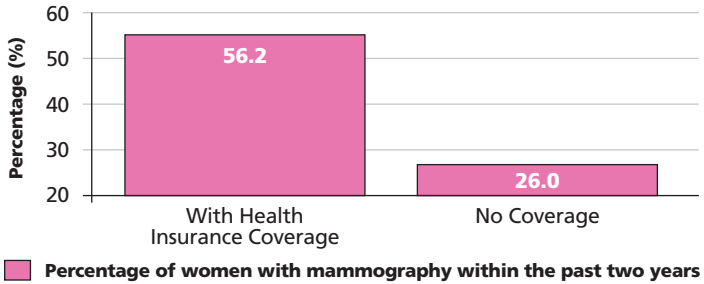
BREAST AND CERVICAL CANCER SCREENING RATES[1]

Breast and cervical cancer screening has been shown to reduce cancer mortality. If detected early, the five-year survival rate for both breast cancer and cervical cancer is more than 90 percent. However, 39 percent of breast cancers are diagnosed at an advanced stage and between 60 percent and 80 percent of women with advanced cervical cancer have not had a Pap test in the past five years.

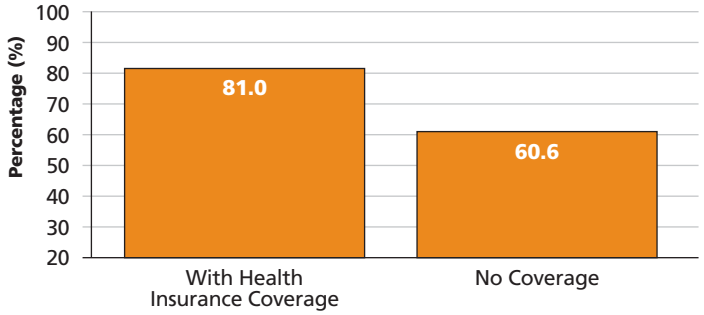
Diagnosis at late stage means survival drops to 23 percent for breast cancer and 17 percent for cervical cancer. Improvements in survival are possible by improving regular use of mammography and Pap test screening and providing timely access to high-quality follow-up and treatment.

Despite the known benefits of regular mammography and Pap test screening in the United States, recent data shows that many women are initiating mammography and Pap test screening later than recommended, not having screenings at recommended intervals, and/or not receiving appropriate and timely follow-up of positive screening results. These indicators of inadequate screening are associated with more advanced tumor size and later stage at diagnosis.

Mammography, Women 40 and Older, US, 2008



Pap Test Use, Women Ages 18 and Older, 2008



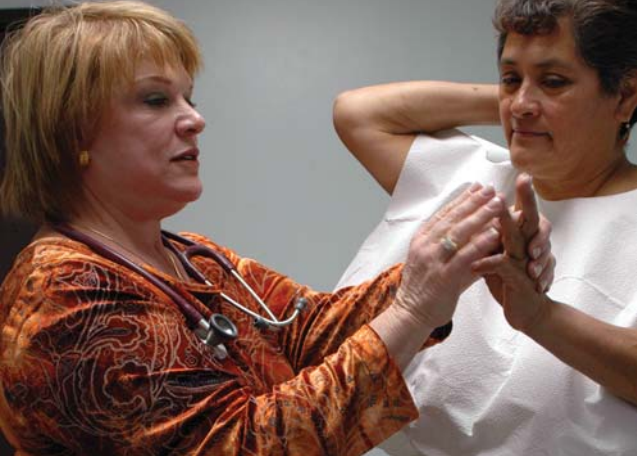
Mammography Screening in the United States

National breast cancer screening data that measures screening within the past year is available from the National Health Interview Survey (NHIS). The NHIS has tracked trends in mammography screening rates since 1987.

- Only 53 percent of women ages 40 and older reported having a mammogram within the past year.
- The lowest prevalence of mammography use in the past year occurred among women who lack health insurance, followed by immigrant women who have lived in the United States for fewer than 10 years.
- Racial and ethnic minorities are significantly less likely than whites to have had a mammogram in the past year.

Pap Test Screening in the United States

- According to data from the NHIS, in 2008, 78 percent of women 18 years of age and older reported having a Pap test within the past three years, up from 74 percent in 1987. Increases in Pap test use have occurred among women of all racial and ethnic groups, except in uninsured women.
- In 2008, the prevalence of Pap test use varied by race and ethnicity: African-American (81.5 percent) and White women (79.6 percent) were most likely to have had a recent test and Asian-American women (63.8 percent) were least likely to have been tested.
- In 2008, the prevalence of recent Pap test use was lowest among women with no health insurance (60.6 percent) and recent immigrants (60.1 percent).



CANCER DISPARITIES

Substantial disparities exist in breast and cervical cancer diagnosis, treatment, and survival among American women. The stage at diagnosis is consistently shown to be more advanced in racial and ethnic minorities, lower income, and uninsured women. Much of the disparities in breast and cervical cancer screening and outcomes are due to underlying differences in income and health insurance and access to quality care. However, language barriers, unhealthy environments, region of residence, cultural and genetic differences, and racial discrimination also play a significant role.

Diagnosis

The stage at which breast and cervical cancer is diagnosed has an enormous impact on five-year survival rates. Chances for five-year survival post-diagnosis decrease when cancer is found at a later stage or when larger tumors are discovered. Stage at diagnosis is consistently shown to be more advanced in racial and ethnic minorities, lower income, and uninsured women. Minority women may be at a higher risk for dying of breast cancer because they are more likely to be diagnosed at later stages, in which treatment is more difficult and prognoses are often worse.[2] Therefore, despite the fact that overall annual screening rates are similar between races, minority women may not be getting screened at adequate intervals or early enough. Additionally, other socioeconomic factors, such as poverty and insurance coverage that do lead to disparities in screening, may account for some of the differences seen between races in stage at diagnosis.[3]

Treatment

Disparities in treatment exist in the areas of breast-conserving surgery versus mastectomy, radiation treatment after breast-conserving surgery and breast reconstruction.

- Recent studies showed that, among women with early breast cancer, racial and ethnic minorities were 20 to 50 percent less likely to receive appropriate treatment.[4]
- African-American women are less likely to receive standard treatments of cancer care even after adjusting for socioeconomic status.[5]
- Due to inequalities in access to care, minority women are more likely to delay follow-up cancer care and treatment, resulting in poorer cancer outcomes.[6, 7]

Mortality

- Mortality rates (per 100,000) are highest in African-American women. Age standardized mortality rates for breast cancer (1996-2000) are 35.9 for African-American women, compared to 27.2 for white women.[6]
- African-American women experience five-year survival rates of 76 percent, which is 14 percent lower than white women at 90 percent. Part of this difference is due to later stage at detection; African-American women have a lower percentage of localized stage at diagnosis and a higher percentage of distant stage at diagnosis.[8]

NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM[1]

"Access to early detection screenings can mean the difference between life and death. The National Breast and Cervical Cancer Early Detection Program has saved thousands of lives by giving low-income and uninsured women access to the care they need to continue living healthy lives. Health care reform builds on that progress. We are now saying goodbye to an era when simply being a woman is treated as a pre-existing condition and saying hello to an era where decisions about whether to receive preventive care and screenings are made by a woman and her doctor, not an insurance company."

U.S. Senator Barbara Mikulski
Maryland

To help improve access to breast and cervical cancer screening among the medically underserved populations in the United States, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990, which authorized the CDC to create the National Breast and Cervical Cancer Early Detection Program (NBCCEDP).

This program, which Congress began funding at $30 million in fiscal year 1991, has grown to a nationwide program with an appropriation of $215 million in fiscal year 2010 for breast and cervical cancer screenings. The program started in five states and, today, provides screening support in all 50 states, the District of Columbia, five U.S. territories and 12 tribes or tribal organizations, representing a vast national network of more than 20,000 health care providers.

The NBCCEDP is designed to increase access to – and improve the quality of – breast and cervical cancer screening nationwide. In particular, it serves low-income, uninsured, or underinsured women, by providing:

- Clinical breast examinations
- Mammograms
- Pap tests
- Pelvic examinations
- Surgical consultation
- Referrals to treatment
- Diagnostic testing for women whose screening outcome is abnormal

To receive screening services through this program, a woman must be uninsured or underinsured, and have an income equal to or less than 250 percent of the federal poverty level (FPL). Women ages 18 to 64, who meet these requirements, are eligible to receive clinical breast exams, pelvic exams and cervical cancer screenings. Women ages 40 to 64, who meet these requirements, are eligible to receive additional screening for breast cancer using mammography through the program.

In addition to providing access to lifesaving screening tests, the NBCCEDP invests in numerous outreach activities. Outreach is essential, especially to serve women who are harder to reach, since they are often also the ones who have never been screened. The NBCCEDP supports an array of strategies, including education, quality assurance program evaluation, partnerships and provider recruitment. These accomplishments demonstrate a truly successful collaborative effort between the federal, state and local government. It builds on the existing public health infrastructure and involves all sectors of the community in the outreach and delivery of services.

States, tribes, and territories that receive funding through the NBCCEDP by law must:

- Spend 60 percent or more of their federal funds on direct clinical services, and 10 percent or less on administrative expenses.

"I am proud to have worked with Republican and Democratic colleagues to ensure that no woman, whether poor or rich, insured or uninsured, dies because she doesn't get treatment in time. While we continue our fight to end cancer forever, this program remains a lifeline, providing millions of women with access to early detection."

U.S. Congresswoman Tammy Baldwin, Wisconsin (2nd District)

- Contribute a match of $1 for every $3 of federal funding received.
- Be evaluated regularly by the CDC.
- Not use NBCCEDP funds to pay for treatment or research.

A comprehensive and coordinated approach to screen and monitor women for breast and cervical cancer is supported by key program components, including:

- Screening women through a health care delivery system.
- Outreach, recruitment, and public awareness activities to inform women of the need for screening and bring eligible women into the program.
- Public education about the risks for breast and cervical cancer, recommended screening intervals and addressing the fears women face.
- Professional education and quality-assurance activities to ensure the use of science-based, clinically appropriate, and high-quality screening and follow-up.
- Surveillance and case management of all women screened to ensure they receive timely follow-up for diagnostic care and referrals to treatment, if needed.

In 2000, Congress passed the Breast and Cervical Cancer Prevention and Treatment Act. This act gives states the option to provide Medicaid coverage to eligible women who are screened and have breast and/or cervical cancer, or pre-cancerous lesions, by the NBCCEDP.

To qualify for Medicaid treatment coverage under this provision, a woman must be under the age of 65, not be otherwise eligible for Medicaid, be without credible health care coverage, be screened by the state's Breast and Cervical Cancer Early Detection Program, and need treatment for breast or cervical cancer.

The act is administered by the Centers for Medicare and Medicaid Services (CMS). To date, all 50 states and the District of Columbia have approved this Medicaid option. In 2001, Congress passed the Native American Breast and Cervical Cancer Treatment Technical Amendment Act, which expanded eligibility to include American Indians/Alaska Natives who are eligible for health services provided by the Indian Health Service or by a tribal organization.

In 2007, The National Breast and Cervical Cancer Early Detection Program Reauthorization Act of 2007 was signed into law by President Bush, authorizing the program for another five years. In June 2007, the CDC awarded funding to 68 programs for a new five-year cycle. The reauthorization included a provision for the CDC to initiate a demonstration project to waive the 60/40 spending requirement for up to five funded programs. The 60/40 requirement specifies that at least 60 percent of the awarded funds must be used for direct clinical services; the remainder may be used for essential public health components to support the screening program.

Programs selected to participate in the demonstration project may use this temporary waiver to strengthen the public health components, including the provider delivery system, outreach, public awareness and education, professional education, quality assurance, partnerships, case management, and tracking screening and follow-up services for up to two years. Additionally, they are required to leverage available non-federal funds with the goal of screening additional women and continuing to expand the level of screening and follow-up services through the duration of the waiver period.

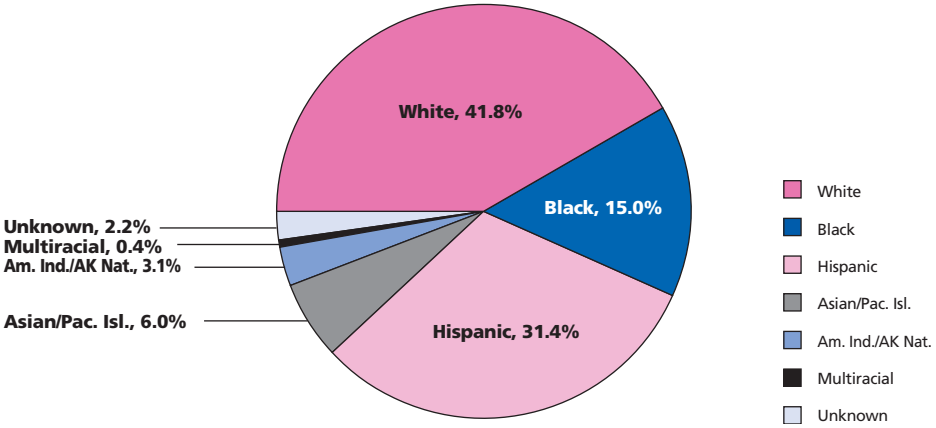
REAL FACES OF THE NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM

Since its establishment in 1991, the NBCCEDP has been implemented in all 50 states, the District of Columbia, four US territories and 13 American Indian/Alaska Native organizations. To date, the program has provided eight million screening exams to more than three million underserved women.

The NBCCEDP program screens more than 500,000 women ever year. In 2008, 310,355 women received mammography screening, while 322,684 women had a Pap test.

The age and race of women screened reflect the program's policies that prioritize breast cancer screening for women between the ages of 50 to 64 and cervical cancer screening for women between the ages of 40 and 64. Thus, women who received a mammogram tended to be older, with more than 70 percent ages 50 to 64.

Demographic Characters of the NBCCEDP: Race/Ethnicity



The program targets racial and ethnic minorities, who tend to have lower screening rates for breast and cervical cancer, evidenced by more than half of the women screened falling into those two categories. The program has a proven track record for helping reduce disparities. In 2009, Virginia's BCCEDP program, Every Woman's Life, conducted a study on the timeliness of breast cancer screening and diagnosis. At 60 days, there were no disparities noted in diagnostic and treatment standards.

The NBCCEDP Provides a Safety Net for Women to Access Lifesaving Mammograms That They Likely Would Not Otherwise Have

Marilyn's Story

Marilyn Douglas, 57, a Caribbean-American mother of two children, was always vigilant about getting a yearly mammogram when she was employed by a company that offered health insurance. Now that she is self-employed, living in Florida, and earning about $900 a month, she is unable to afford health insurance coverage.

Marilyn experienced abnormal breast symptoms last year and, because of her knowledge of breast cancer, she knew she should get a mammogram to check for cancer. Since her usual mammography facility had closed, she called the Florida Breast and Cervical Cancer Early Detection Program to find out about free screenings in her area. Marilyn was told that a mobile mammography van was scheduled to be in her neighborhood, so she got a breast checkup and mammogram promptly. She also had a Pap test to screen for cervical cancer and received information about menopause symptoms, a possible reason for her breast pain. According to Marilyn, "If it weren't for this program I would not have been able to get my screenings done." She was happy with her experience with the Florida Breast and Cervical Cancer Early Detection Program and plans to call them this year to schedule her annual mammogram so that she can stay well.

"This year marks the twentieth anniversary of the establishment of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). This landmark federal legislation, establishing programs in 68 states, territories and tribes, targets uninsured and underinsured women who are particularly vulnerable to health disparities due to breast and cervical cancer. Across the nation many great success stories are shared, but the work is not yet done. With the economic downturn over the past three years, many programs now find themselves stopping screening and putting women on wait lists, as resources are limited. The need for services, including support services that address health disparities, like patient navigation and case management, has significantly increased due to women losing jobs that provided health insurance."

NBCCEDP Council

Elveta's Story

Elveta Verhoeve is a 44-year-old Caucasian woman from Virginia who has been married for 19 years. She has a 16-year-old child whom she home schools and is not employed outside the home.

Elveta never had a mammogram, but her mother's breast cancer diagnosis in July 2009 forced her to take a serious look at her own breast health. Although Elveta has health insurance through her husband's employer, mammograms are not covered on their plan, and the deductible was too much for her to afford.

She called her local cancer center to find out where she could have a free mammogram. The cancer center referred her to a local hospital, where she was told there was a program that could assist her. Elveta called Every Woman's Life and was given a pre-screening interview, followed by a full screening interview. She was told that a cervical cancer screening would take place first, and that she would have the mammogram at a later date. Since there was a clinic in her area only once a month, she had to wait a few weeks for her first appointment.

About three weeks after her cervical cancer screening appointment, she received a letter stating that her results were negative. Elveta then scheduled her mammogram, which was done at a different location. She was relieved to find out that her mammogram screening showed no abnormalities.

Elveta plans to use the Every Woman's Life services on an annual basis, and has spread the word among her friends that such an important program is available to eligible women who want to take charge of their health and stay well. (Elveta is pictured right.)

"As a breast cancer survivor, I know the importance of regular screenings. American women shouldn't die from cancer because they struggle to afford screenings or access to treatment. I'm proud of the program, and prouder still those women who are screened and learn that they have cancer can get the treatment they need to get healthy."

Congresswomen Sue Myrick
North Carolina (9th District)

Improving Outreach and Education

Raising awareness about the importance of breast and cervical cancer screening and community outreach programs is important to reducing disparities. The NBCCEDP helps increase awareness by ensuring education efforts are culturally competent and easily understood and by bringing cancer education and screening services directly to medically underserved women using peer networks and community health liaisons. By using community liaisons, the NBCCEDP can help empower women in hard-to-reach populations to get screened and improve awareness.

Ernestine's Story

Ernestine Brooks is a 56-year-old single African-American woman with two adult children, ages 37 and 35. Since 2000, she has been working full time as a child care provider in her home in Virginia. Being self-employed, she receives no health insurance benefits. Her average monthly income is less than $1,000, which leaves her unable to purchase an affordable insurance policy.

For many years, Ernestine has had frequent breast lumps, which prompted her to seek out medical attention when she was only in her 20s. At that time, her employer provided health insurance and she was able to access mammography services easily on a regular basis. On two occasions, her mammograms showed potential abnormalities, which required biopsies. Ernestine was relieved to find that both biopsy results were negative.

Not long after that, Ernestine lost her health insurance benefits. She heard about Every Woman's Life through a neighbor and promptly called for an appointment. Enrollment in the program proved to be a simple process. During the first phone contact, Ernestine discovered that she met program eligibility requirements and scheduled her first appointment.

Over the nearly 10 years that Ernestine has been enrolled in Every Woman's Life, she has been pleased with the services she's received. She believes she has received "wonderful care" and that the staff "treats me like a special person." She appreciates the fact that the facility is convenient to her and that she is sent a reminder each year to schedule her annual appointment.

Ernestine never misses an opportunity to tell her friends and family about the valuable and potentially lifesaving services Every Woman's Life offers. Her hope is that all women who are eligible for the program will take the time to care for themselves by getting regular breast and cervical cancer screenings and stay well.

PROVIDING ACCESS TO LIFESAVING TREATMENT

"Today we recognize the countless women who were able to access lifesaving screenings and treatment because of the successful National Breast and Cervical Cancer Early Detection Program. It is critical that we continue to support important programs like these as we work together to find a cure for breast and cervical cancer."

U.S. Senator Debbie Stabenow, Michigan

The Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) established a coverage option under Medicaid that permits states to extend benefits to any uninsured woman under 65 who has been screened and diagnosed with breast and/or cervical cancer under the NBCCEDP. The creation of a Medicaid coverage option by the BCCPTA was groundbreaking because it was the first effort to use a population-based public health screening program as a pathway to publicly funded health insurance, resulting in new interagency partnerships at both the federal and state levels. By creating this unique disease-based category for Medicaid coverage, the BCCPTA has generated considerable interest as a viable policy approach for addressing the challenges of uninsured women facing serious illness.

Under the BCCPTA, women have full Medicaid coverage throughout the duration of their breast or cervical cancer treatment. They also have access to case managers who help them navigate through the health care system from diagnosis to survivorship.

Gail's Story

As one of nine children, Gail Carey (pictured right) learned at a young age the importance of helping out around the house, especially since both of her parents worked. When her mother developed emphysema and had to stop working, the family struggled financially. Her parents later separated, forcing Gail, her mother and her siblings to turn to Medicaid for health coverage.

Her mother always reminded them that Medicaid was only a temporary remedy, not a permanent solution; it was a hand-up, not a hand-out. After her mother passed away, Gail was inspired to find a good job that would provide health benefits. She was fortunate to find a position with an advertising and trade show company in New York.

After the attacks of 9/11, the New York trade show market collapsed, and Gail, along with 90 percent of her co-workers, lost her job. Losing a job also meant losing her health insurance benefits. Having separated from her husband in 2000, Gail had no one to rely on for assistance. A few weeks after losing her job, she found what felt like a lump in her breast. Having had previous work experience in the mammography division of a health care facility, she knew how important it was to get the lump checked out quickly – but she couldn't afford to pay for a screening.

After a couple months of job hunting, Gail was hired by a company that promised health insurance benefits after three months. She waited the required three months before asking her boss about health benefits, indicating that she had a health concern that needed to be addressed immediately. Instead of receiving the benefits she was promised, Gail was fired on the spot. So she was again out of a job and stranded without the benefits she needed.

Five months after she first detected the suspicious lump, Gail was still uninsured. For women with breast cancer, five months could be

the difference between life and death. Fortunately, a friend working for a hospital on Long Island told Gail about a brand new program in New York called The Healthy Women's Partnership, New York's version of the NBCCEDP. Gail scheduled a doctor's appointment with a Healthy Women's Partnership provider to get the screening process under way. Doctors confirmed the lump in her breast was in fact cancerous, and Gail was referred to a surgeon who subsequently performed a lumpectomy. Since he was not sure he removed all of the cancer, the surgeon performed a follow-up full mastectomy a month later.

Throughout the entire process, Gail had help navigating through her appointments and the follow-up treatments, including medications, which were all covered by Medicaid. Gail says she feels truly blessed to have found the NBCCEDP program, which covered her screening and ensured she would have access to all the treatments required. Without them, she likely would not have survived. Throughout this whole ordeal, she said was treated with such dignity.

"This program is a phenomenon," she says. "I thought I was going to die because I didn't have the necessary medical coverage or the means to pay for my treatment. Nobody should have 'giving up' as their only option. **The NBCCEDP is crucial to women who find themselves in an impossible situation with no place to turn.**"

"The impact of this program is more extensive than you may think, since it impacted not just my well-being, but also the lives of my children, my family and friends. Since my treatment, I have lived to see my oldest daughter get married and just recently became a first-time grandmother to an extraordinary grandson. This program is crucial to women like me – who find themselves in an impossible situation, with no place to turn. This program is a godsend not only to me, but to anyone who is fortunate to know it exists. I am eternally grateful."

Despite NBCCEDP's proven success, the program's funding is woefully inadequate and has failed to keep pace with inflation. This means that fewer than one in five eligible women currently receive screenings through the NBCCEDP.

Patient Navigator Programs

Navigating the health care system can be a daunting journey for many people, especially when they are poor, underinsured or uninsured. Patient navigators help people stay well and overcome barriers to health care – from screening to diagnosis, to treatment and beyond.

Patient navigators rely on local resources and people who already work in community health centers, clinics and local hospitals to identify patients who may need help. These community liaisons assist people in need by:

- Providing community outreach and counseling on disease prevention and healthy lifestyle choices.
- Promoting early detection screening tests.
- Providing assistance in obtaining referrals for treatment.
- Scheduling follow-up appointments and arranging transportation.
- Ensuring medical instructions are understood and followed.
- Helping patients find funds to pay for doctor visits and treatments.
- Addressing other barriers to health care that medically underserved individuals often face.

WHAT ABOUT THE OTHER FOUR? HOW BREAST AND CERVICAL CANCER PATIENTS SLIP THROUGH THE CRACKS

So, What about the Other Four?

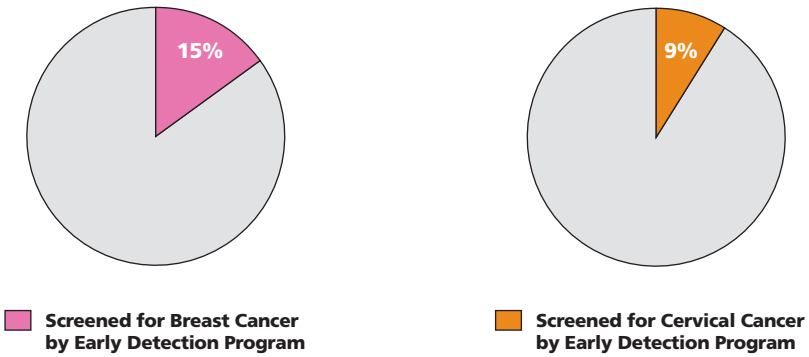
While NBCCEDP is successful, the severe underfunding means fewer than one in five eligible underserved, uninsured or low-income women have access to these lifesaving screenings and treatment services. Many more lives can be saved through this program.

In August 2007, President Bush signed the National Breast and Cervical Cancer Early Detection Program Reauthorization Act, acknowledging the success of the program and setting a funding target of $275 million annually for five years. But Congress only approved $205 million for NBCCEDP in fiscal year 2009 and $215 million for fiscal year 2010.

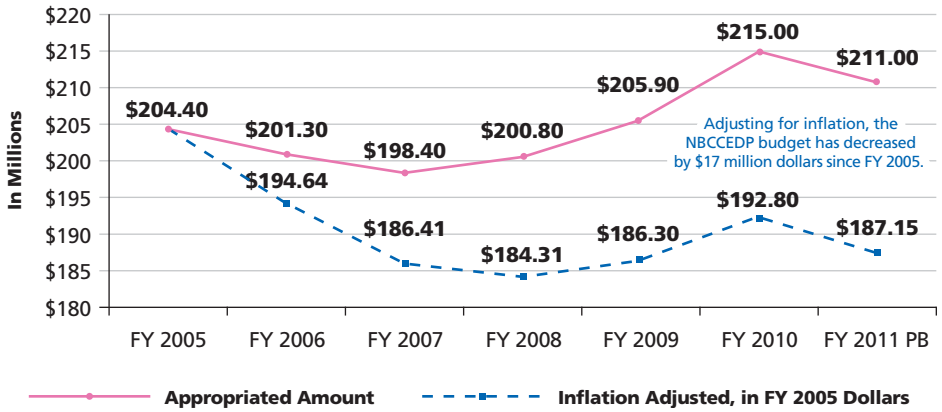
The demands on the program have increased greatly, given the recent turmoil in the job market, which has resulted in millions of additional women without health insurance.[1] As a result, many screening programs have – or will – run out of funds before the end of the current program year, due to two principal causes: 1) They are screening significantly more women for cancer; 2) A higher proportion of the women they are screening are uninsured, which means that all of the diagnostic tests are paid for by the program.

Despite the increased need and demand for the program, many states are also slashing funding to the NBCCEDP. This year alone, at least 17 states[2] have decreased their state budget for the screening program, which means more women across the United States will needlessly lose their lives. In order to reach as many eligible women as possible, ACS CAN and the Society urge both federal and state legislatures to continue appropriating dollars for this underfunded program.

Eligible Women Can't Participate in NBCCEDP Due to Lack of Funding



Federal Funding for NBCCEDP Has Not Kept Pace with Inflation



"CDC is excited to be celebrating the 20th anniversary of its National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Since inception, the NBCCEDP has provided lifesaving screenings to more than 3.6 million women and detected more than 160,000 cancers or pre-cancers. CDC has worked collaboratively with the advocacy community to expand the reach of the NBCCEDP and is extremely proud of the impact this program has made on women's health across the nation."

Marcus Plescia, M.D., M.P.H., Director of Division of Cancer Prevention and Control at CDC

Lack of Funding Has Forced Programs to Turn Women Away

Many states are forced to turn women away or have long wait lists due to insufficient funding. This is not ideal because it seems to suggest that eligible women are being promised services that can't be delivered. The "system delay" between experiencing symptoms and diagnosis may also negatively affect prognosis. Finding cancer as early as possible can potentially spare a large number of women invasive and unpleasant treatment procedures and their associated costs (e.g., actual charges, effect on quality of life, and lost income due to time away from work).

Lorinda's Story

Lorinda McFerran, age 41, has always understood the importance of early detection. Her mother died of breast cancer at the age of 62, and her maternal grandmother was diagnosed with the disease when Lorinda was just a young girl.

Due to her family history, Lorinda's doctor recommended that she start getting mammograms and women's health checks regularly starting at age 35. She was referred to St. Lawrence County's Cancer Services Program, where she received annual cancer screening tests for the past seven years. During that time, she was diagnosed with an abnormal mass. Fortunately, it was not cancerous, but her doctors stressed the importance that she continue to get annual tests to monitor her condition. Every year since then, she has received an annual mammogram through her the New York State Breast and Cervical Early Detection Program. The program provided all the services she needed, helped with paperwork, was attentive to her needs, and even provided transportation to and from the clinic, if she couldn't find a ride.

This year, however, after Lorinda received her reminder card in the mail and she called to make her appointment, she was informed she couldn't come in for her mammogram or Pap test because the program had run out of funds. She knew the importance of getting a mammogram, but in her county there were very few options to get an affordable test. The mobile mammography van provided by the local hospital ran out of funding and discontinued the program last year. The current economy has made it difficult for her to find a job that offers insurance, and the cost of paying for a mammogram out-of-pocket would be financially devastating.

Lorinda is concerned about not getting tested this year, considering her family history for breast cancer and her need to monitor the abnormal mass. "This year, the mass could have changed into something cancerous and I won't know."

"Here in North Country in New York State, it is a great struggle to get medical attention. There just aren't medical options in the area. The program is really important for people in this region, especially now with everyone strained financially. The Cancer Services Program is absolutely critical, and the people who work there are wonderful. It really helps save lives … if you can get in."

Funding Limits Have Caused Programs to Apply Age Limits

Because of funding restrictions, NBCCEDP cannot screen all the women who are at risk for breast or cervical cancer. The majority of the funds must be dedicated to screening women between the ages of 50 and 64 for breast cancer and between 40 and 64 for cervical cancer, which leaves younger women to fend for themselves. Many states do not even screen women under the age of 50 for breast cancer or under the age of 40 for cervical cancer.

Regina and Rachel: A Mother's and Daughter's Story

Regina Peterson, 51, of Michigan didn't tell anyone for four years that she had a lump in her breast because she didn't have the insurance or financial means to have it checked. After learning about the growing mass, her five children became extremely concerned about her health and took it upon themselves to research resources that were available to help pay for a doctor's visit. The program connected Regina to a local provider who participated in Michigan's Breast and Cervical Cancer Early Detection Program. He diagnosed her with an aggressive form of breast cancer, and by the time Regina had the tumor removed in December 2009, it was almost as large as an orange.

During one of Regina's consultations, her eldest daughter, Rachel, 31, mentioned she also discovered a lump on her breast and the doctor immediately ordered a biopsy. A few days later, Rachel was told she also had breast cancer.

Because both women were uninsured, their doctor referred them to the Breast and Cervical Cancer Early Detection Program, which would provide free cancer screenings and a gateway to treatment, if diagnosed. Regina was quickly accepted into the program and had her tests and treatment expenses covered. However, Rachel, who made less than $7,000 from two part-time jobs, was told she didn't qualify for the program because she was too young. She applied to Medicaid twice but was denied because she didn't have any children.

Rachel and Regina are currently undergoing treatment; however, both women have had very different experiences with the health care system. Regina is a beneficiary of the Breast and Cervical Cancer Prevention and Treatment Act and has had a good medical and support team that helps her navigate through the system. Rachel, on the other hand, has astronomical medical bills, some exceeding $18,000 for just one round of chemotherapy. Rachel also can't work right now; her treatments make her highly susceptible to infections and her doctors warned that she must stay away from large crowds, which her job at a concert arena requires. As a result, Rachel, the oldest of Regina's five children, has no income and has applied for disability benefits so she can help out her family financially.

The Petersons are extremely grateful that their doctors haven't denied Rachel care because of her insurance status, but they don't understand why a program that was created to help women won't accept Rachel because she is too young. The family relies on Regina's and Rachel's incomes to cover expenses. However, because they are both in treatment and cannot work, the Petersons are facing serious financial issues, including possible bankruptcy. (Regina and Rachel pictured right.)

Breast Cancer in the 40 to 49 Age Group

Approximately 18 percent of female breast cancer cases are diagnosed in women ages 40 to 49, or about 34,600 new cases this year.

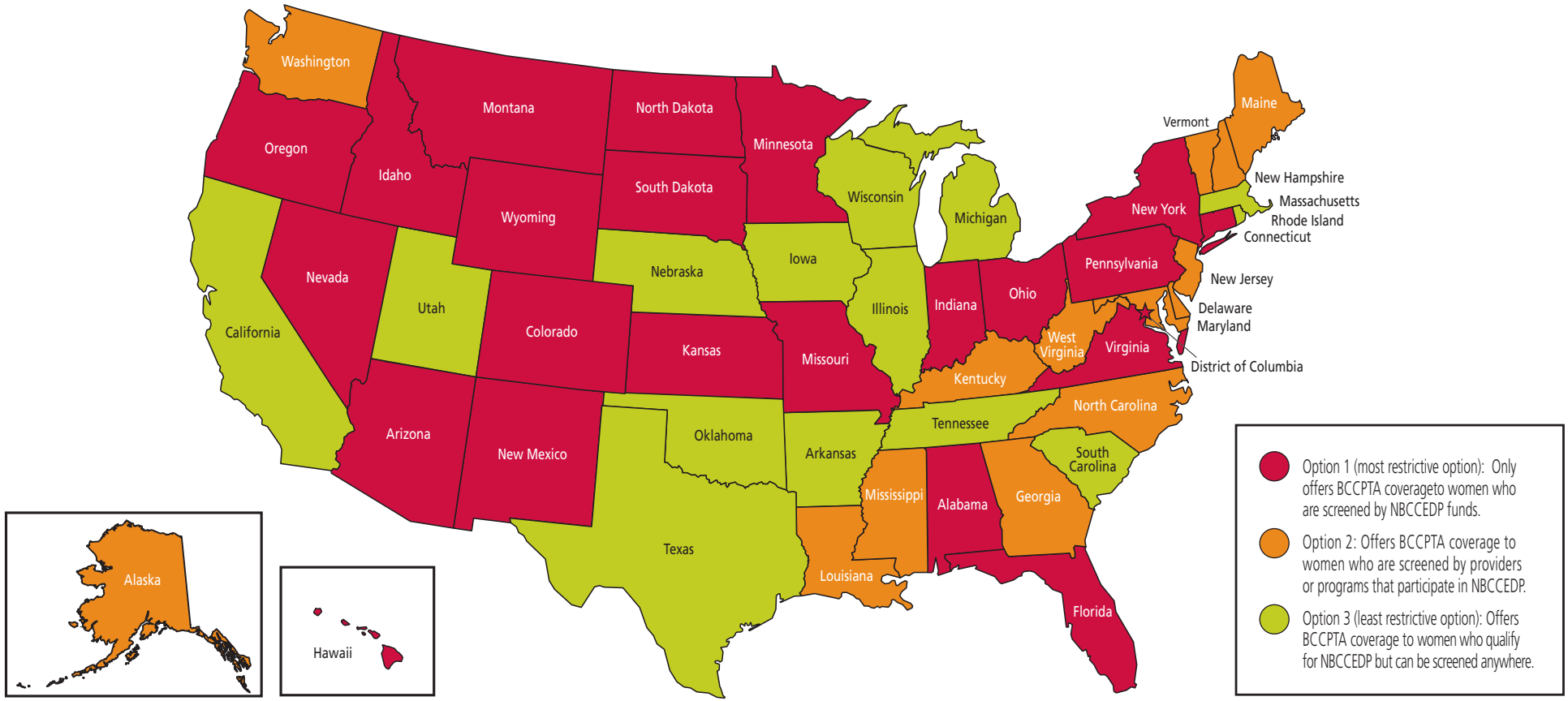
Mammography screening has reduced breast cancer mortality rates by 15 percent in women ages 40 to 49, and these declining rates are directly correlated to screening and early detection of the disease.

Current evidence supporting mammograms in women ages 40 to 49 is even stronger than in the past. Women can feel confident about the benefits associated with regular mammograms for finding cancer early. They should be told about the benefits, limitations and potential harms linked with regular screening. Mammograms can miss some cancers, but despite their limitations, they remain a very effective and valuable tool for decreasing suffering and death from breast cancer.

Loopholes in the Program Deny Women with Breast and Cervical Cancer Coverage for Treatment

In some states, women diagnosed with cancer cannot qualify for Medicaid treatment unless they received their screening from a limited pool of providers. Congress gave states the option to implement the BCCPTA law either generously or more restrictively. Under the generous option, states can grant Medicaid coverage to all eligible women regardless of where their cancer is diagnosed. Under the more restrictive option, they can deny coverage to women diagnosed outside a federal cancer-detection program. Twenty-one states chose to do the latter. In those states, women such as Shirley, who would have qualified for the screening program, but their cancer was not detected through a participating provider, are not eligible for this Medicaid coverage. Other women, like Meaghan, could have benefited from BCCPTA coverage, but eligibility restrictions had resulted in insurmountable medical debt.

BREAST AND CERVICAL CANCER TREATMENT COVERAGE BY STATE



Shirley's Story

On September 13, 2007 the Wall Street Journal[3] featured the story of Shirley Loewe. A hairdresser in Texas, Shirley didn't have health insurance, and her income ($15,000 a year) was too high for her to qualify for Medicaid the traditional way. In 2003, when Shirley was diagnosed with her cancer, Texas participated in the most restrictive option, requiring that screenings be paid with NBCCEDP funds to qualify for to BCCPTA. Because Shirley was diagnosed at a non-NBCCEDP clinic, rather than a different NBCCEDP clinic a few blocks away, Shirley couldn't get covered for her treatment. Shirley cut back her work hours to reduce her income, which allowed her to qualify for traditional Medicaid. However, her reduced salary meant she could no longer afford to pay rent, and she was forced to move out of her home.

If Shirley had been covered by Medicaid from the time she was diagnosed, she might have received needed care sooner and may have survived her breast cancer. She died in 2007 at the age of 55. (Shirley is pictured right.)

Texas has since changed its rules so that it doesn't matter where a woman is diagnosed. But similar rules still apply in 22 states and the District of Columbia.[4]

Meaghan's Story

Meaghan Edelstein, who was a 28-year-old law school student in Florida in the winter of 2007, dreamed about the many opportunities awaiting her. However, during her second year of classes, she began feeling ill.

Insured with Mega Life through the American Bar Association, Meaghan went to numerous doctors looking for help. Because she was young and had always been healthy, the doctors assumed nothing could be seriously wrong. Enduring extreme pain, bleeding, and exhaustion, she kept returning to her doctors for help. No one did anything to address her health issues, and her symptoms gradually became worse with each passing day. Because no one believed she was ill, Meaghan continued to attend classes and tried to live a normal life.

Eventually the pain became so unbearable that she drove herself to the ER. A CT scan revealed a tumor that had grown so large it had crushed her insides, causing her kidneys to rip open. In February 2007, Meagan was diagnosed with stage 3b advanced cervical cancer. The same doctors who had assured her that everything was fine were now telling Meaghan and her family that she would not survive.

Meaghan was fortunate to know an OB-GYN nurse-practitioner who was able to get her an appointment with a world-renowned oncology team at Dana-Farber Cancer Institute in Boston, Mass.

"One of the doctors [at the Dana-Farber Cancer Institute] looked at me with tears in her eyes. She said to my father and me, 'I cannot imagine the pain you must have endured. I can see this happening in a third-world country but not here. ' "

That is how Meaghan began her long journey with cancer, which included chemotherapy, radiation and multiple invasive surgeries. Much of the treatment was excruciatingly painful and left her unconscious. Once she regained consciousness, she discovered her health insurance carrier dropped her, claiming the cancer was a "pre-existing condition" and she knew about her cancer when she

"The District of Columbia has one of the lowest uninsured rates in the country (as a result of DC Health Alliance, a public program that provides free health care to low-income individuals and families), however, rates of screening for breast cancer are at only twelve percent. The District of Columbia does not lack resources for breast cancer screening, however, resources are not dispersed adequately both geographically and with community providers where the need is. Additionally, varying and changing eligibility criteria for public assistance, provider reimbursement rates, and a fragmented health care delivery system with limited provider choices (i.e. all but three of the major District hospitals do not take DC Alliance) compound the problem."

Beth Beck, Executive Director of the Capital Breast Care Center, currently the largest provider of screening services funded under the DC's NBCCEDP program

got the coverage. Meaghan was devastated, but it was too late to fight them to reinstate her coverage. Her insurer denied coverage for any of her medical expenses, even the office visits before her diagnosis.

With her family's help, she was able to qualify for MassHealth disability coverage, which helped cover the care she received at Dana-Farber Cancer Institute. However, MassHealth couldn't cover the care Meaghan received in Florida, and she amassed $100,000 in medical bills that she couldn't afford to pay. Furthermore, when Meaghan returned to Florida to finish law school, she couldn't qualify for health insurance through the individual market or get access to Medicaid because the Florida BCCPTA program didn't accept women who were not screened by a BCCEDP provider.

As a result, Meaghan is still on MassHealth and has been forced to make regular trips to Boston for her continued care. She pays thousands of dollars for travel and hotel costs because she can't get health insurance in Florida and is unable to afford to see any of the doctors who live near her. Meaghan recently discovered there are support services that are available to help with transportation and lodging. If she'd had access to a patient navigator earlier in her treatment, she would have been able to apply for these services instead of paying for flights and increasing her debt due to her cancer diagnosis.

Meaghan, now 32, has started an advocacy organization to raise awareness about cervical cancer, especially in young women, and hopes that no other person has to experience what she went through.

Women Who Move from One State to Another May Be Denied Coverage for Treatment

Despite federal guidance that says women who move from one state to another do not have to be re-screened, a few states restrict access to Medicaid if their state program did not screen them.[5] This interpretation of the law causes delays in treatment that could be life-threatening to a patient who is fighting for her life. For example, if a woman moves to Florida, she would be denied coverage to Medicaid, even if she qualifies for BCCPTA or another public health insurance program, and is undergoing active treatment in a different state. BCCPTA is supposed to provide a safety net for women, but it doesn't always work.

Low-Income Women Have a Difficult Time Finding Doctors Who Participate in the Screening Program and Medicaid

NBCCEDP and the Medicaid program has improved access to care for low-income patients who would otherwise lack health insurance. However, many physicians do not participate in NBCCEDP or Medicaid, limiting the effectiveness of the program in enhancing access to care.

In a 2009 report from the Center for Studying Health System Change, a nonprofit research group based in Washington, nearly half of all doctors polled said they had stopped accepting or limited the number of

new Medicaid patients.[6] That's because many state Medicaid programs are balancing their budgets by freezing or reducing payments to doctors. That in turn is driving many doctors, including oncologists, out of the program.

State Variations in Defining Standard of Care Have Resulted in Termination of Coverage, Even When Cancer Treatment is Needed

Breast and cervical cancer treatment can be brutal for patients both physically and psychologically. Treatment may include a combination of surgery for the removal of tumors, radiation therapy, chemotherapy, biologic therapy, hormone therapy, pain management and reconstructive surgery. For some women, active treatment may continue for many years if they are prescribed hormone therapy to help prevent recurrence and improve survival. Treatment for breast and cervical cancer is often associated with painful and chronic side effects, including swelling (lymphedema), mouth sores, a high risk of infection, nerve damage, heart damage and changes in the menstrual cycle.

Standard care for conditions and side effects associated with breast and cervical cancer treatment is often not covered by the Medicaid BCCPTA program. The Centers for Medicare and Medicaid Services (CMS) has given states flexibility in defining standard of care. Consequently, there is great variation in adequacy of state coverage. Furthermore, even if a woman needs long-term cancer treatment, such as hormone therapy or medical attention due to treatment complications, she may have to go through a re-determination process or may even have her Medicaid benefits terminated, leaving her without coverage.

Isis' Story

Isis Souffrin, 38, is battling cancer for the third time. The divorced mother of five was diagnosed with breast cancer in 2004, ovarian cancer in 2005, and a recurrence of breast cancer in 2008. She is unemployed, unable to work and receives $500 per month in child support. She has Medicaid coverage, but isn't able to get the dental care or prescription drugs that she needs.

During treatment for her cancer, Isis' gums became inflamed, which required her to have some teeth extracted. Florida's Medicaid program would not cover her dental care. As a result, her cancer treatment was delayed for six weeks while she searched for a dentist to perform the surgery.

Isis has also had to forgo necessary prescriptions because they are not on the Medicaid formulary, and she cannot afford them. She currently weighs less than 100 pounds and needs appetite stimulants to increase her weight. Medicaid does not cover these drugs, and she cannot afford the $400 per month generic alternatives. She is taking herceptin as part of her breast cancer treatment, but she has said her doctors are having difficulty getting Medicaid to cover it. She is unsure if she will be responsible for the final costs.

Isis also faces difficulty keeping up with her co-pays for doctor visits and prescriptions. She is unsure of the level of medical debt she will face when her battle with cancer is over.

What is Medicaid Re-Determination?

Enrollment in Medicaid under the Treatment Act can also be affected by state policies and practices for periodic re-determination of Medicaid eligibility. Medicaid re-determination is a process in which the state periodically confirms the eligibility of a beneficiary. Federal law requires states to re-determine beneficiary eligibility every 12 months, however, many states have more frequent re-determinations for some eligibility categories. This is sometimes used by states as a process to increase barriers to enrollment. Practices for re-determining eligibility can range from a statement by the beneficiary that she continues to need treatment, to a verbal or signed statement by the health care provider of the beneficiary's treatment status. This practice has resulted in decreased access in many states. For example, in West Virginia, Medicaid enrollment declined from 709 in 2004 to 247 in 2006 after the state imposed stricter re-determination requirements in 2004.[7]

HOW THE HEALTH CARE REFORM LAW WILL HELP CANCER PATIENTS

For the first time in years, meaningful health care reform has been enacted that will benefit families affected by cancer by emphasizing prevention, expanding access to meaningful coverage, and improving quality of life for cancer patients and survivors. The health care reform law, The Patient Protection and Affordable Care Act, will significantly improve access to quality screening and treatment for women with breast and cervical cancer.

The Affordable Care Act will give women and their families the relief they need from skyrocketing health insurance costs, and will ensure Americans have secure, stable, and affordable health insurance.

Approximately 160 provisions in the final health care legislation will directly impact the millions of Americans who have – or will face – cancer. Following is a list of the most important provisions for women facing breast and cervical cancer.

I. Enhancing the Role of Disease Prevention and Early Detection

- Guarantees coverage and eliminates out-of-pocket costs for pap tests and mammography.
- Establishes a fund, to be administered through the Office of the Secretary at the Department of Health and Human Services (HHS), to provide for an expanded and sustained national investment in prevention and public health programs.
- Strengthens the primary care workforce through student financing, additional primary care residency programs at teaching health centers, and training in cultural competency, prevention and public health.
- Significantly increases community health center funding.

II. Meaningful Coverage: Availability, Affordability, Adequacy and Administrative Simplification

A. Private insurance

Availability

- Provides immediate access to coverage for uninsured people with a serious pre-existing condition through the high-risk pool, affording a transition coverage until full implementation of the legislation.
- Eliminates pre-existing condition medical restrictions for most private insurance plans by 2014.
- Prohibits all plans from rescinding coverage, except in instances of fraud or misrepresentation.
- Guarantees availability and renewability of coverage.

Affordability

- Limits insurance premium variation to family structure, geography, the actuarial value of the benefit, age (limited to a ratio of 3 to 1), and tobacco use (limited to a ratio of 1.5 to 1).
- Creates refundable tax credits to provide premium assistance for individuals and families, up to 400 percent of the federal poverty level, for coverage under a qualified health plan.
- Limits out-of-pocket maximums for individuals and families enrolling in qualified health plans.

Adequacy

- Eliminates lifetime and annual limits for most plans.
- Requires insurance plans to cover essential health benefits.
- Administrative simplicity.

B. Medicaid

- Expands eligibility for individuals with income below 133 percent of the federal poverty level (FPL) and optional coverage for those above 133 percent of FPL.
- Generally prohibits states from reducing or dropping breast and cervical cancer treatment eligibility during transition period until 2014.
- Offers incentives for coverage of preventive services for eligible adults in the Medicaid program.
- Permits states to use incentives to encourage enrollees to participate in chronic disease prevention programs.
- Simplifies enrollment in Medicaid.
- Improves Medicaid reimbursement rates for primary care physicians, fostering increased access for patients.

C. Medicare

- Begins an immediate reduction in Part D prescription drug coverage gap (e.g., the "doughnut" hole).
- Improves Medicare coverage of annual wellness visit, including a personalized prevention plan.
- Eliminates cost-sharing and deductibles in Medicare for U.S. Preventive Services Task Force prevention services with "A" or "B."

III. Improving Quality of Life for Cancer Patients and Survivors

- Reauthorizes HHS's Patient Navigator program, which assists patients with maneuvering through the health care system, provides outreach and education for patients to encourage preventive screenings, and addresses needs that may impact compliance with screening and treatment.
- Requires commercial health insurance plans and the Federal Employee Health Benefits Plan (but not private self-insured plans) to cover the patient care costs associated with participation in clinical trials that are approved or funded by a variety of federal agencies.
- Requires the Secretary of HHS to establish national priorities and plans for improving the quality of health care, including care coordination and chronic disease management.
- Authorizes Institute of Medicine conference and report on pain management and enhanced coordination of NIH pain research, and establishes grant program to improve health professionals' understanding and ability to assess and appropriately treat pain.

THE FUTURE OF NBCCEDP

"I am a proud supporter of the Every Woman Matters Breast and Cervical Cancer Screening Program. Since its inception in 1991, the Every Woman Matters program, administered by the Nebraska Department of Health and Human Services, has screened 60,000 + women for breast and cervical cancer. Among those women who are our friends and neighbors across Nebraska, 781 have been diagnosed with breast cancer and 60 have been diagnosed with invasive cervical cancer. It is without question that the services provided to women under the Every Woman Matters program have provided peace of mind, improved health outcomes and saved women's lives.

I was very proud to work with the American Cancer Society to introduce and pass legislation, Legislative Bill 369 in 2009, that almost doubled existing state funding for the program so that more women will have access to prevention, screening and treatment services to ensure early detection is expanded and more lives can be saved."

Nebraska State Representative
Danielle Conrad

While the health care reform law will greatly improve insurance coverage, the NBCCEDP program will remain an essential program for improving access to breast and cervical cancer screening and treatment in our nation's most vulnerable populations. It will be critical to use the program's infrastructure and community outreach specialists to help women and their families enroll in the various insurance options for which they qualify.

ACS CAN has determined that the NBCCEDP will also ensure continuity of care for women and their families. The following list describes how the program will continue to protect women's lives:

- *Provide access to lifesaving screening tests.* While health care reform will greatly expand health insurance coverage in the United States, millions of women will remain uninsured. The NBCCEDP will still play a role in providing these women with access, not only to breast and cervical cancer screening services, but also potentially to other preventive services for which they may be eligible.

- *Continue to educate women about the importance of early detection.* Since its inception, NBCCEDP has targeted education and outreach efforts to low-income women to help raise awareness about the importance of early detection of breast and cervical cancers through screening. One of the most effective ways to improve communications between patients and providers is through community outreach. The NBCCEDP program uses culturally competent health educators to encourage medically underserved women to get screened and to emphasize the importance of timely follow-up care.

- *Improve public health infrastructure and coordination of care.* Coordination between stakeholders is critical to ensure the success of a public health program. The NBCCEDP will continue to be the leader in the development, production and statewide distribution of joint, consistent public education messages.

- *Get women enrolled in health insurance.* Many vulnerable populations are considered "hard to reach" because the availability of coverage alone does not ensure enrollment. At least 25 percent of the uninsured are eligible for public insurance programs. This lack of enrollment has been attributed to a number of factors, including lack of information, lengthy application processes and documentation requirements, and concerns about costs. The NBCCEDP can help alleviate some of the reasons that keep individuals from initial enrollment and prevent them from renewing coverage or re-enrolling.

- *Help women navigate the health care system.* Choosing a health plan, finding a provider, and navigating a complex and opaque health care system can be especially intimidating for populations that have limited experience with health insurance and the health care system. The NBCCEDP program can provide women with culturally appropriate information and help alleviate confusion and frustration with health system processes, which can prevent them from seeking available health care services.

- *Ensure needed care is covered and affordable.* For low-income populations, the cost of health care is particularly important and cancer care can be expensive. The NBCCEDP can help alleviate financial issues by helping with co-payments associated with cancer care.

- *Address psychosocial and cultural barriers to care.* Racial, ethnic and sexual minority groups are more likely to encounter language and other cultural barriers, stigma and discrimination, and to receive lower quality care. The NBCCEDP can help ensure that women who are diagnosed with cancer get access to appropriate support services, which can help alleviate barriers to quality cancer care.

Even with the vast improvements in health insurance coverage in the Affordable Care Act, the population served by NBCCEDP will continue to need education and outreach, adequate coverage and navigation. With proper planning, it is possible to transform the program to adapt to the changing needs of low-income women.

Conclusion

Breast and cervical cancer have become two of the most preventable and increasingly curable life-threatening diseases – but only if the steps necessary are taken for prevention, early detection and access to quality care.

The only way progress can continue to be made in the fight against breast and cervical cancer is by working to ensure that women continue getting regular mammograms and Pap tests, which can detect cancer at its earliest, most treatable stage.

While great strides have been made with the passage of the Affordable Care Act, much work remains to be done to increase screening in medically underserved populations. The nation should make a commitment to remove any barriers to breast and cervical cancer screening and treatment for low-income and minority women. The NBCCEDP helps accomplish this, but current funding is not sufficient to continue the progress this program has made in reaching increasing numbers of women who might not otherwise receive these lifesaving tests, nor is the program's current funding sufficient to maintain a steady pool of providers. Furthermore, it is critical that the CMS enhances oversight of the treatment program to ensure that all states provide adequate, quality care to women undergoing cancer treatment and fighting for their lives.

The goal of the American Cancer Society and ACS CAN is to save lives from breast and cervical cancer by ensuring that all women have access to existing and future detection methods and treatments in order that they can stay well and get well. As a result of these efforts, our mothers, sisters, wives and friends will celebrate more birthdays along with 11 million cancer survivors across the United States. The Society and ACS CAN stand ready to work with federal, state and local governments to help achieve this goal.

"As a member of both the Joint Finance-Appropriations Committee and House Health and Welfare Committee, I believe it is important to provide strong and consistent leadership in the fight against cancer. This past session, I was pleased to lead the effort to secure state funding for the Breast and Cervical Cancer Early Detection Program (BCCEDP).

The BCCEDP provides lifesaving services to women every year. Early detection is the key. We make a high return on our investment when we invest in preventative medicine. From a policy perspective, it makes sense to invest money in preventative programs, which save money, and more importantly, save lives for women in Idaho.

In my capacity as a state representative, I will pledge my continued leadership and support in the fight against cancer."

Idaho State Representative
Janice McGeachin

MAKING STRIDES AGAINST BREAST CANCER® THROUGH ADVOCACY: A PARTNERSHIP THAT MAKES A DIFFERENCE

Making Strides Against Breast Cancer® is the American Cancer Society's premier event to raise awareness and dollars to fight breast cancer. More than just the name of a walk, it describes the amazing progress we're making together to defeat this disease. These events give participants the opportunity to join their community to celebrate breast cancer survivors, educate women about the importance of early detection and prevention, and raise money to fund lifesaving research and support programs to help us reach a day when no one will have to hear the words "You have breast cancer."

2005 — "One in Five" Postcard Campaign

During the inaugural year of the Making Strides Against Breast Cancer and advocacy partnership, participants nationwide supported the "One in Five" postcard campaign. They urged Congress to ensure that all women have access to lifesaving mammograms, with the goal of reauthorizing and funding the National Breast and Cervical Cancer Early Detection Program (NBCCEDP).

The response was amazing: more than 18,000 postcards were signed at Making Strides events and delivered to members of the U.S. House of Representatives in Washington, D.C. And at the end of 2006, the House voted in favor of the reauthorization.

2006 — Save Mammograms/"Red Bra" Campaign

The U.S. Senate tried to pass legislation that would have gutted the existing laws in 49 states that required insurance companies to cover mammograms. ACS CAN and Making Strides Against Breast Cancer participants immediately took action with the "Red Bra" campaign.

ACS CAN placed ads in local papers throughout the country and on line, and sent action alerts to volunteers in opposition of this dangerous piece of legislation. More than 30 percent of all Making Strides Against Breast Cancer participants who received this email took action by emailing their senator.

We won! In an article in The New York Times, ACS CAN was credited with defeating this harmful measure.

2006 — "What About the Other Four?" Campaign

Although the "Save Mammograms" campaign was a huge victory for ACS CAN, advocates were still needed to push Congress to reauthorize the NBCCEDP. In 2006, the focus was on the U.S. Senate.

Thousands of petitions were signed at Making Strides Against Breast Cancer breakfasts and walk events, sent back to Washington, D.C., bound into books and delivered to their U.S. senators. In part, because so many Making Strides participants took action, the U.S. House and Senate voted in favor of the reauthorization of the NBCCEDP.

2007 — "We Can Change the Odds" Campaign

With the NBCCEDP reauthorized, the 2007 postcard and petition campaign focused on urging Congress to fund the lifesaving program. As always, Making Strides Against Breast Cancer participants from around the country took immediate action. More than 32,000 postcards and petitions were signed, sent back to Washington, D.C., and delivered to U.S. senators during Breast Cancer Awareness Month.

2007 — President Bush signed the reauthorization of the NBCCEDP into law.

After all of the hard work of Making Strides Against Breast Cancer participants, the NBCCEDP was reauthorized in early 2007. At an event held at the Roosevelt Room in the West Wing of the White House, the president signed the bill into law in front of an American Cancer Society and ACS CAN volunteer who had been served by the NBCCEDP.

2008 — "What If It Were Me?" Campaign

Urging Congress to fund the lifesaving programs of the National Breast and Cervical Cancer Early Detection Program was the focus for the 2008 postcard petition campaign. In force, Making Strides Against Breast Cancer participants took action at breakfasts, kick-offs, and at Making Strides events all around the country. More than 40,000 postcards and petitions were signed and delivered to U.S. senators in their home states during Breast Cancer Awareness Month.

2008 — "Fight Back Express" Campaign

The Fight Back Express bus visited Making Strides Against Breast Cancer events to help highlight the challenges of accessing health care. The bus traveled to more than 500 events across the country. It completed its tour in Washington, D.C., carrying more than 50,000 signatures asking Congress to make cancer a top national priority.

2009 — "Someone Isn't Getting Screened" Campaign

As in years past, this campaign urged Congress to fully fund the NBCCEDP. With thousands of Making Strides Against Breast Cancer participants signing petitions, more than 50,000 petitions were delivered to members of Congress. This campaign highlighted the fact that "Someone Isn't Getting Screened" who was eligible and turned the tables to ask "What if it Were You?" The message continued to resonate and helped provide a slight increase in federal funding.

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