



**Our Vision:** A world where no one dies from breast cancer—and ultimately, where no one ever gets it.

**Our Mission:** To end breast cancer through the power of action and advocacy.

## Our Priorities

**Research:** NBCC creates new models of research, brings significant funding to scientists for meaningful research, and oversees how funds are spent.

NBCC leads collaborations that set research priorities and change systems. Through our Artemis Project®, advocates and scientists work side-by-side to identify and answer the questions vital to ending breast cancer.

NBCC's Clinical Trials Initiative ensures trained breast cancer survivors are included in the entire planning and implementation process and that policies encourage access to trials and mandate insurance coverage for participants.

**Access:** NBCC believes everyone should have access to the care they need, and no one should be denied coverage due to an inability to pay.

NBCC works to improve access to quality breast cancer care for all, from appropriate screening policies to diagnosis, treatment, and care—particularly for the underserved and uninsured—through legislation and change in the delivery of health care.

NBCC developed a framework for a system and principles of quality care that includes coverage of evidence-based, meaningful, and cost-effective care; increased efficiency; and improved communication.

**Influence:** NBCC demanded—and won—a place for advocates wherever breast cancer decisions are made: in Washington, DC and state capitals, laboratories and health care institutions, and communities everywhere.

NBCC empowers advocates to bring an informed patient perspective in designing research, determining quality care, establishing a legislative agenda, and other highly specialized areas of breast cancer activism. Science education programs like Project LEAD®, public policy academies, and leadership training sessions prepare lay advocates to meaningfully impact research, public policy, and health care.

NBCC and NBCC advocates tell the truth about breast cancer and work to change the conversation from awareness to action.

## Our Values

- **Urgency:** We must end breast cancer now.
- **Tenacity:** Until breast cancer is ended, we will never give up and will never back down.
- **Questioning:** We challenge the status quo, view everything with a critical eye, and analyze all information before we act.
- **Courage:** We ask hard questions and make difficult decisions. When the evidence dictates, we reject popular or accepted thinking.
- **Knowledge:** We do our homework and make strategic choices based on evidence.
- **Inclusion:** We require diversity of thought, action, and perspective in everything we do. We want everyone at the table.
- **Focus:** We strategize how to have meaningful impact; we bring about real change.
- **Integrity:** We are committed to our mission and hold ourselves and others accountable for positions and actions taken.
- **Innovation:** We challenge ourselves and others to create new models and approaches.
- **Compassion:** No one else should suffer.

## Our Accomplishments

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**Building a Thousands-Strong Grassroots Advocacy Network:** NBCC links hundreds of organizations and tens of thousands of individuals nationwide in a dynamic, diverse coalition to achieve our mission and give breast cancer advocates a meaningful voice.

**Creating the Department of Defense (DOD) Peer-Reviewed Breast Cancer Research Program (BCRP):** NBCC advocacy led to the creation of the DOD BCRP—and more than \$4 billion in new federal funding for breast cancer research. NBCC advocates monitor funding and ensure dollars are well spent on meaningful research.

**Educating Thousands of Breast Cancer Advocates:** More than 2,500 advocates have graduated from the Project LEAD Institute, a training program in the language, concepts, and processes they must understand to participate in breast cancer research. Thousands have attended the annual Advocate Leadership Summit, gaining exposure to the latest thinking on and leading minds in research and public policy. Our Public Policy Academy gives advocates additional training and knowledge on the ins and outs of Congress, empowering them to push for change on Capitol Hill.

**Implementing the National Action Plan on Breast Cancer:** NBCC grassroots advocates delivered more than 2.6 million signatures on a petition to President Clinton, sparking the launch of the National Action Plan on Breast Cancer and resulting in a greater emphasis on women's health initiatives from the White House.

**Increasing Access to Care:** NBCC drafted and fought for the passage of federal and state laws ensuring that underserved and uninsured women diagnosed with breast or cervical cancer were guaranteed access to quality treatment, launching a system of health care for tens of thousands of women.

**Leading New Approaches to Metastatic Breast Cancer Research:** Through NBCC's Artemis Project and other research work, top researchers and trained advocates work together to set research priorities and design and implement research plans, moving us closer to knowing how to prevent metastasis and stop deaths from breast cancer.

**Shaping Clinical Trials:** NBCC has been a key partner in many seminal clinical trials, working with research organizations to improve trial design and monitoring, increase access and accrual, educate the medical community and consumers, and promote the initiation of high-quality breast cancer trials.

**Spearheading a Preventative Vaccine:** Artemis Project participants have created a strategic plan for a preventative vaccine, identified vaccine targets, and begun pre-clinical work. The vaccine is now moving toward a Phase 1 clinical trial.

## Our Accolades

NBCC is a **four-star CharityNavigator nonprofit**, a **Better Business Bureau Accredited Charity**, and a **gold-level GuideStar/Candid participant**. NBCC has an **"excellent" rating from the American Institute of Philanthropy** for effective use of funds raised and was identified by Charity Watch as a **top-rated breast cancer charity**.

## Join Us. Save Lives.

Visit [stopbreastcancer.org](http://stopbreastcancer.org) to learn more about NBCC's work to end breast cancer-- and how you can support our mission.





# 2026 Legislative and Public Policy Priorities

## Legislative Priorities

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### PRIORITY #1

**\$150 Million/Level Funding for the Department of Defense (DOD) Breast Cancer Research Program (BCRP) for FY2026:** As a result of NBCC's grassroots advocacy, the DOD BCRP was created in 1992 to end breast cancer for service members, veterans, and the general public by funding innovative, high-impact research through a partnership of scientists and consumers. The DOD BCRP is widely viewed as an innovative, unique, and efficient medical research model that has proven to be accountable to the public and has produced extraordinary results. NBCC seeks continued level funding.

### PRIORITY #2

**Metastatic Breast Cancer Access to Care Act:** This legislation would waive the 24-month waiting period for Medicare and the 5-month waiting period for Social Security Disability Insurance benefits for eligible individuals with Metastatic Breast Cancer.

### PRIORITY #3

**Preservation of the Medicaid Breast and Cervical Cancer Treatment Program:** Congress enacted the Breast and Cervical Cancer Treatment Act in 2000 after years of NBCC grassroots lobbying and influence. NBCC remains committed to ensuring all women and men screened and diagnosed with breast cancer have access to the treatment they need.

## Public Policy Priorities

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### PRIORITY #1

**Guaranteed Access to Quality Care for All:** Ensuring access to quality evidence-based health care has been a top priority of NBCC for many years. NBCC supports healthcare access initiatives that expand access to Medicare while offering a private insurance option, automatically enrolling individuals who do not have access to other coverage and providing guaranteed benefits, including primary and preventive care, hospital services, and prescription drug coverage. NBCC believes that there must be shared financial responsibility and that no individual should be denied coverage due to an inability to pay.

### PRIORITY #2

**Protect Scientific Research:** NBCC recognizes the importance of the scientific process and infrastructure that have led to many life-saving interventions and enhanced our knowledge of the human condition. NBCC supports policies and legislation that protect the advancement of scientific knowledge and research through federally funded programs. NBCC will oppose policies and legislation that undermine the scientific process and infrastructure that result in credible, high-quality science.

### PRIORITY #3

**Access to Affordable and Effective Therapies:** NBCC supports policies that address systemic deficiencies in the law, regulation, and science policy that result in the approval of drugs that do not significantly extend or save lives and whose prices are not based on value or effectiveness.

### PRIORITY #4

**Food & Drug Administration (FDA) Reform:** NBCC supports a drug approval system that prioritizes approving drugs with clinically meaningful benefits for patients. NBCC seeks to address systemic deficiencies in FDA regulation and the drug development process, including reforms to the accelerated approval pathway and the use of unvalidated surrogate endpoints.

### PRIORITY #5

**Ensure the Participation of Educated Patient Advocates in Science Research and All Levels of Health Care Decision-Making:** NBCC continues to work to ensure that educated patient advocates who are trained and represent a constituency have a meaningful seat at the table in all levels of health care decision-making that affects their lives.



## \$150 Million for the Department of Defense (DOD) Peer-Reviewed Breast Cancer Research Program (BCRP) for FY2027

### Background

The DOD BCRP was created in 1992 as a result of the National Breast Cancer Coalition's "\$300 Million More" campaign to increase federal funding for breast cancer research. Due to NBCC's efforts and the congressional leadership of Senators Tom Harkin (D-IA) and Alfonse D'Amato (R-NY) in FY1993, Congress appropriated \$210 million in the DOD research and development budget for a breast cancer peer-reviewed research program administered by the Department of the Army. As a result of NBCC's grassroots advocacy and the DOD BCRP's demonstrated success, Congress has appropriated funding for it each year since.

### A Model Medical Research Program

Since its inception, the DOD BCRP has sought to "eradicate breast cancer by funding innovative, high-impact research through a partnership of scientists and consumers." It has grown from a small research program to a far-reaching, influential model that others have sought to replicate throughout the cancer and broader medical research community.

Some keys to the DOD BCRP's success:

- **It is innovative and unique.** The DOD BCRP has a unique grant structure that allows it to be more flexible than other traditional competitive, peer-reviewed medical research programs. This structure can fund innovative, high-risk, high-return research and quickly respond to current scientific advances. The DOD BCRP can also fill gaps by focusing on promising but otherwise underfunded research areas. In its reviews of the DOD BCRP, the Institute of Medicine has stated "the program fills a unique niche among public and private funding sources for cancer research. It is not duplicative of other programs and is a good vehicle for forging new ideas and scientific breakthroughs in the nation's fight against breast cancer."
- **It is efficient.** Due to the program's flexibility, the Army can administer it with unparalleled efficiency and little bureaucracy. The program allows approximately 90% of the appropriated funding to go directly to competitive, peer-reviewed research grants awarded to the best science.
- **It is accountable to the public and transparent.** Information on all funded grants is posted on the program website, accessible to the public. In addition, educated, trained consumer advocates participate in a two-tiered process where research proposals are reviewed for scientific quality and programmatic relevance. This consumer involvement allows grant funding decisions to be informed by trained breast cancer survivors and based on patient and medical communities' concerns and needs. It provides for those who have no agenda other than to end breast cancer for everyone. This transparency allows scientists, consumers, and the public to view the progress made in breast cancer research through the DOD BCRP.
- **It has produced extraordinary results.** From new methods of extracting breast cancer cells at their earliest stages to unprecedented research into gene/environment interaction to quality-of-life issues, the DOD BCRP leads the way in generating new approaches to breast cancer prevention and treatment. It has produced fascinating insights into the biology of breast cancer. It has directly impacted lives through the research it has funded, such as the revolutionary work that led to the development of the innovative drug Herceptin.

The DOD BCRP owes its success to the integrated efforts of its partners—from the ongoing dedication of the US Army and their belief and support of this mission, to the members of Congress who support the program through continued funding, to the scientists and consumers who participate, and to the researchers who every year submit proposals that reach the highest level asked of them by the program.



NATIONAL BREAST CANCER COALITION

# DEPARTMENT OF DEFENSE BREAST CANCER RESEARCH PROGRAM (DOD BCRP)

**7,350+**  
GRANTS  
AWARDED

**19,691**  
PUBLICATIONS

**1,383**  
PATENTS

**222**  
CLINICAL  
TRIALS

**50+**  
PRODUCTS IN  
CLINICAL  
TRIALS OR  
DEVELOPMENT

**25**  
PRODUCTS ON  
THE MARKET

**2,500,000+**  
PEOPLE  
TREATED

In 1992, in response to grassroots advocacy led by the National Breast Cancer Coalition (NBCC), Congress established the Department of Defense Peer Reviewed Breast Cancer Research Program (DOD BCRP). Since then, Congress has appropriated **more than \$4.3 billion** to support this vital initiative. These funds have driven lifesaving and transformative discoveries in breast cancer research.

To date, the program has awarded over **7,358 competitive grants**, contributing to the development of **25 commercialized products** and resources, and supporting **more than 50 promising therapies** currently in clinical trials or under development. The program has resulted in **more than 1,300 patents** and **19,500 publications** in scientific journals. The impact of this work spans all facets of breast cancer, improving outcomes for millions of individuals—including members of the military and their families.

A defining feature of the DOD BCRP is its rigorous two-tier application review process, which brings together scientists, clinicians, military personnel, and educated consumers from the breast cancer community. In addition, trained breast cancer advocates are involved throughout the research continuum, ensuring that the research remains relevant, patient-centered, and grounded in the real-world experiences of those affected by the disease.

## SUCCESSFUL BREAST CANCER TREATMENTS ADVANCED THROUGH THE SUPPORT OF DOD BCRP FUNDING INCLUDE:

### HER2 Targeted Therapy

**Drug name:** Trastuzumab (Herceptin)

**Type of breast cancer treated:** HER2+ (*HER2=Human Epidermal Growth Factor Receptor 2*)

**How does it work?** Herceptin is a monoclonal antibody that targets HER2, a protein found in excess on some breast cancer cells. It works by blocking cancer cell growth and signaling the immune system to attack the tumor. At the time of its development, many were skeptical—previous antibody therapies had failed. But with critical support from the DOD BCRP, Herceptin defied expectations. It became the first targeted therapy to dramatically change outcomes for a specific subtype of breast cancer and is now a cornerstone of treatment for HER2-positive disease.

**Impact:** Over 25 years of transforming care. More than 2.4 million people treated worldwide. Herceptin didn't just extend lives—it fundamentally changed them. Once considered one of the most aggressive forms of breast cancer, HER2-positive disease is now one of the most treatable, thanks to this groundbreaking therapy.

**Legacy:** Herceptin marked the beginning of a new era in oncology. It proved that targeting the molecular drivers of cancer could lead to more effective, personalized treatment—and it set the standard for how we develop and deliver cancer therapies today. Its success inspired an entire class of HER2-targeted drugs, reshaped clinical trial design, and fueled global efforts to ensure equitable access to life-saving treatments. Herceptin's legacy continues to influence cancer care and research around the world.

### CDK4/6 Inhibitors

**Drug name:** Palbociclib (Ibrance), Ribociclib (Kisqali), and Abemaciclib (Verzenio)

**Type of breast cancer treated:** HR+ HER2- (*HR=hormone receptor [estrogen and/or progesterone]*)

**How does it work?** Rather than directly killing the cancer cells, CDK4/6 inhibitors work by blocking the proteins that allow cancer cells to grow and divide. This helps to slow or stop cancer's ability to proliferate.

**Impact:** Ibrance was the first new treatment option in over a decade for this subtype of breast cancer and has been used to treat more than 450,000 breast cancer patients. Following its approval, Kisqali and Verzenio were introduced, offering additional, meaningful benefits—most notably, the potential to help patients live longer.

### Selective Estrogen Receptor Modulators

**Drug name:** Tamoxifen (Nolvadex)

**Type of breast cancer treated:** ER+ (*ER=estrogen receptor*)

**How does it work?** Tamoxifen is a type of hormone therapy that blocks estrogen from fueling the growth of cancer cells. It works by binding to estrogen receptors, preventing estrogen itself from attaching and stimulating cancer growth.

**Impact:** Tamoxifen significantly reduces the risk of breast cancer recurrence and death in people with ER+ disease. The ATLAS clinical trial—supported in part by funding from the DOD BCRP—showed extending tamoxifen treatment from 5 to 10 years can further enhance its benefits, cutting breast cancer mortality in half during the second decade after diagnosis.

### Prone Radiation Therapy

**Type of breast cancer treated:** Early stage

**How does it work?** Radiotherapy uses radiation to kill cancer cells and can decrease the risk of cancer returning, but the radiation can damage surrounding healthy tissue.

**Impact:** In DOD BCRP-funded projects, researchers found that providing radiotherapy to a patient in the prone position (facing down) instead of the supine position (facing up) can spare the heart and lungs from significant radiation exposure.

## PROMISING RESEARCH AREAS WITH PRODUCTS CURRENTLY ADVANCING THROUGH CLINICAL TRIALS BENEFITTING FROM DOD BCRP FUNDING INCLUDE:

### Vaccines and Immunotherapies

**Goal:** Stimulate or alter the patient's immune system to help their immune cells to kill cancer cells currently in their body, train their immune cells to prevent breast cancer cells from returning, or prevent breast cancer in the first place.

**The potential:** 22 products are in clinical trials, with 1 product in the final stage of the clinical pipeline (Phase 3 trial).

### Diagnosis, Prognosis, and Risk Assessment

**Goal:** Create sensitive and accurate technologies for determining one's risk of breast cancer, why and how some breast cancers become metastatic, and distinguishing deadly from non-deadly breast cancer.

**The potential:** 3 products are currently in clinical trials. Importantly, beyond the clinical pipeline, more than 10 products in this area have made it to the market and are currently used to diagnose, evaluate risk of, or predict best treatment plans for breast cancer.

### Therapeutics

**Goal:** Kill cancer cells, stop cancer cells from growing and spreading, or prevent breast cancer in the first place, with minimal toxicity and maximal benefits.

**The potential:** More than 30 treatments are in clinical trials, with 3 new treatments in the final stage of the clinical pipeline (Phase 3 trial). Importantly, beyond the clinical pipeline, several treatments in this area have made it to the market and are currently used to treat breast cancer patients.

### FOR MORE INFORMATION ON THE DOD BCRP:



DOWNLOAD THE FEBRUARY  
2025 BCRP PROGRAM BOOK



DOWNLOAD THE BCRP  
PROGRAM SUMMARY SHEET

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*To learn more about NBCC, please visit [stopbreastcancer.org](http://stopbreastcancer.org).*



# Metastatic Breast Cancer Access to Care Act (S. 3442, H.R. 2048), 119th Congress

## **Legislation to waive the 24-month waiting period for Medicare and the 5-month waiting period for Social Security Disability Insurance benefits for eligible individuals with metastatic breast cancer.**

### **Background**

Metastatic breast cancer is cancer that has spread from the breast to the bones, lungs, or other distant parts of the body. Unfortunately, 90% of breast cancer deaths are a result of metastatic disease. There are treatments, some of which have extended survival for women and men with metastatic breast cancer, but today, there is no cure.

Individuals diagnosed with metastatic breast cancer automatically qualify for disability benefits from the Social Security Administration (SSA) and for Medicare coverage regardless of age, as long as they apply and meet the SSA's technical qualification rules. An individual must have been employed within the last 10 years and currently unable to work due to their disability to earn Social Security disability insurance benefits (SSDI). Once an individual is approved for SSDI, there is a 5-month waiting period to begin receiving benefits and a 24-month waiting period for Medicare coverage.

### **Federal Precedent for Extended Coverage**

Applying waiting periods to individuals with a lethal disease like metastatic breast cancer is arbitrary and cruel. The National Breast Cancer Coalition urges Congress to enact legislation to amend the Social Security Act to eliminate waiting periods for disability insurance benefits and Medicare coverage for eligible individuals with metastatic breast cancer.

In 2001, Congress passed a bill to add Amyotrophic Lateral Sclerosis (ALS) as a qualifying condition for automatic Medicare coverage and, in 2020, waived the 5-month waiting period for SSDI for individuals with ALS, thus creating a federal precedent. Based on the limited life expectancy of individuals with metastatic disease—an average of 3 years—NBCC believes that both automatic SSDI and Medicare coverage should also apply to metastatic breast cancer patients who qualify.

### **Action Requested**

NBCC urges Congress to enact legislation to amend the Social Security Act to waive all waiting periods for Medicare and SSDI for eligible individuals with metastatic breast cancer.



## Organizational Supporters of the Metastatic Breast Cancer Access to Care Act

ABCD: After Breast Cancer Diagnosis  
ACA Consumer Advocacy  
Adelphi NY Statewide Breast Cancer Hotline & Support Program (NY)  
African American Breast Cancer Alliance, Inc.  
Alamo Breast Cancer Foundation (TX)  
American Association of Breast Care Professionals  
American Association on Health and Disability  
Annie Appleseed Project (FL)  
Ann's Place  
  
Babylon Breast Cancer Coalition (NY)  
Black Women's Health Imperative  
Breast Cancer Action  
Breast Cancer Angels  
Breast Cancer Care & Research Fund  
Breast Cancer Coalition of Nevada (NV)  
Breast Cancer Coalition of Rochester (NY)  
Breast Cancer Education Association  
Breast Cancer Hawaii (HI)  
Breast Cancer Over Time  
Breast Cancer Research Advocacy Network  
Breast Health Collaborative of Texas (TX)  
Brem Foundation to Defeat Breast Cancer (MD)  
  
Cancer Foundation for New Mexico (NM)  
Cancer Resource Center of the Finger Lakes (NY)  
Cancer Services of Eastern North Carolina (NC)  
Cancer Support Now (NM)  
CARE Advocates Network

Cedar Valley Cancer Committee: Beyond Pink TEAM (IA)  
Cedars Sinai Breast Center  
Coalition to Transform Advanced Care  
Colorado Breast Cancer Coalition (CO)  
Coalition for Women's Cancers (NY)  
Colorado Cancer Coalition (CO)  
Connie Dwyer Breast Cancer Foundation (NJ)  
  
Delaware Breast Cancer Coalition (DE)  
Diondai's Place Breast Cancer (IL)  
Don't be a Chump! Check for a Lump!  
Dr. Susan Love Research Foundation  
  
Ephraim McDowell Commonwealth Cancer Center (KY)  
Every Woman Can (WA)  
  
Florida Breast Cancer Foundation (FL)  
  
Gateway to Hope (MO)  
Georgia Breast Cancer Coalition Fund (GA)  
Gilda's Club Twin Cities (MN)  
Global Breast Care Initiative  
GRASP (Guiding Researchers and Advocates to Scientific Partnerships)  
  
Health & Medicine Policy Research Group (IL)  
Health Care Voices  
HIS Breast Cancer Awareness (NJ)  
  
Jack's Caregiver Coalition  
  
Islip Breast Cancer Coalition (NY)



Latina Sisters Support Inc  
Living Beyond Breast Cancer  
Lobular Breast Cancer Alliance

Male Breast Cancer Global Alliance  
Masonic Cancer Center, University of Minnesota (MN)  
Metastatic Breast Cancer Alliance  
Metastatic Breast Cancer Network  
Metastatic Cancer Initiative  
Metavivor  
Michigan Breast Cancer Coalition (MI)  
Minnesota Breast Cancer Coalition (MN)  
Minnesota Young Survival Coalition (MN)  
My Breast Cancer Support

National Breast Cancer Coalition  
National Health Law Program  
National Partnership for Women & Families  
National Women's Health Network  
National Women's Law Center  
New Hampshire Breast Cancer Coalition (NH)  
North Fork Breast Health Coalition (NY)  
Nueva Vida  
Nurses Affecting Change (WI)  
Nurses for America

Ohio Nurses for America (OH)  
Oncology Nursing Society

Pink Aroostook  
Pink Ribbon Good (OH)  
Project Life

Reconstruction of A Survivor  
Reproductive Health Impact: The Collaborative for Equity & Justice

Saving Pennies 4 A Cure  
SHARE  
Sharsheret  
Side-Out Foundation VA)  
Sisters R Us Circle of Survivors  
Sisters Working It out (IL)  
South Carolina Appleseed Legal Justice Center (SC)  
Splash of Color Breast Cancer Support Group  
St. Elizabeth Healthcare (IN, KY)  
Strategic Facilities Planning

Tennessee Breast Cancer Coalition (TN)  
Tigerlily Foundation  
Think Beyond Pink  
The Thinking Woman's Guide to Breast Cancer (CA)  
Theresa's Research Foundation (IL)  
Triage Cancer  
Triple Negative Breast Cancer Foundation  
Twisted Pink (KY)

Urban League of Portland (OR)  
Virginia Breast Cancer Foundation (VA)

West Islip Breast Cancer Coalition (NY)  
Wisconsin Breast Cancer Coalition (WI)  
WNY Ovarian Cancer Project, Inc. (NY)

Young Survival Coalition  
Zero Breast Cancer

*Last updated: 10/22/25*



# Preservation of the Medicaid Breast and Cervical Cancer Treatment Program

## Background

After years of NBCC grassroots lobbying and influence, Congress enacted the Breast and Cervical Cancer Treatment Act (P.L. 706-354) in 2000. This law expanded access to health care for thousands of underserved women. The Act authorized enhanced matching funds to states to provide Medicaid coverage to uninsured or underinsured women diagnosed with breast or cervical cancer through a federal screening program. All 50 states, the District of Columbia, 5 US territories, and 72 American Indian/Alaska Native tribal organizations opted into the Breast and Cervical Cancer Treatment Program (BCCTP). **NBCC remains vigilant in ensuring that the program endures and that eligible individuals continue to receive the lifesaving screening and treatment they deserve.**

## Importance of Maintaining the BCCTP

Before the BCCTP, women diagnosed through the federal Centers for Disease Control and Prevention (CDC) screening program—ineligible for Medicaid coverage yet unable to afford insurance on their own—were falling through the cracks. Following diagnosis, the legacy system left them to rely on an unreliable system of dwindling charity care. NBCC recognized this system's injustice and continues to believe that a federally funded program to screen and diagnose women with breast cancer must include a treatment component.

Since 1991, National Breast and Cervical Cancer Early Detection Program (NBCCEDP) funded programs served more than 5.8 million women. The program provided more than 15.1 million breast and cervical cancer screening examinations and diagnosed 71,107 invasive breast cancers and 4,863 cervical cancers.

In May 2009, the Government Accountability Office (GAO) published a report looking at the status of the Breast and Cervical Cancer Treatment Act, "Source of Screening Affects Women's Eligibility for Coverage of Breast and Cervical Cancer Treatment in Some States." The report identified the screening source requirements as a barrier to women's eligibility for treatment in some states. A follow-up report was published in October 2020, "Federal Programs Provide Screening and Treatment for Breast and Cervical Cancer." GAO analysis of CDC data showed that as a result of Medicaid expansions enacted through the Affordable Care Act (ACA), some low-income women had additional resources for screening and treatment beyond the NBCCEDP, accounting for the reduction in the number of women screened through the program from 2011 through 2017. Additional barriers listed in the 2020 report, like the 2009 report, included certain requirements to qualify for the program.

Under the BCCTP, states must extend Medicaid eligibility to women or men whose screening or diagnostic services were paid specifically with CDC funds. States can be more generous in expanding Medicaid coverage under the BCCTP but cannot fall below this minimum standard. While implementing health care reform through the ACA increased access to breast and cervical cancer screening for low-income, underserved women, efforts to cut expanded insurance coverage and eliminate cost-sharing threaten their access to screening and treatment.

Even with adequate health insurance, many people still face significant obstacles to obtaining breast and cervical cancer screening and treatment due to geographic isolation, limited health literacy or self-efficacy, inconvenient times to access services, and language barriers.

We must not move backward in our progress, even in the face of budget challenges. We must critically examine the impact of any changes to Medicaid, Medicare, or other existing laws based on the effect these changes will have on overall access to quality care.

**NBCC remains committed to ensuring all women and men diagnosed with breast cancer have access to the treatment they need.**



# Ensuring the Participation of Educated Patient Advocates in Science Research and All Levels of Health Care Decision-Making

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## Background

The voice of educated patient advocates must be part of all levels of health care decision-making that affects their lives. Patient participation has been a tenet of the National Breast Cancer Coalition (NBCC) since its inception. NBCC continues to ensure that educated patient advocates who represent a constituency have a meaningful seat at the table in all levels of health care decision-making that affects their lives.

## Why Patient Advocates are Necessary

Educated patient advocates provide a unique perspective that others cannot offer. They are the ones who ultimately receive health care services and, along with their families, are required to navigate the complexities of the health insurance and health care delivery systems. They have no agenda in the scientific community other than looking for the best science and saving lives; they have no conflict of interest. Their perspective cannot be duplicated by the doctors who care for them or the scientists searching for answers, even if these doctors and scientists are patients.

**A lay advocate perspective is key to moving forward to the end of breast cancer.**

## Criteria for Patient Advocates

Patient advocates must:

- Have a patient-led, patient-centered organization with a patient constituency to which they are responsible and accountable;
- Have been personally affected by the disease; and
- Be knowledgeable, trained, prepared, and confident in their ability to participate in the decision-making process of science and medicine.