



Every 13 minutes, a woman dies of breast cancer.

Today, 110 women will die in the United States, and by yearend that number will exceed 43,000 women and 530 men. Worldwide nearly 685,000 women will die.

These numbers represent our family members, friends, and loved ones. Isn't it time to Stop the Clock once and for all?

Don't wait another minute.

Here are 8 ways to get involved and take action to end breast cancer!

- **1.** Join NBCC as a Member. Join with thousands of individuals and hundreds of organizations fighting to end breast cancer.
- **2.** Lend Your Voice. Contact your elected officials about today's top issues. Simply enter your name and address and hit send.
- **3.** Learn More About Policy Issues. Read our legislative and public policy priorities to learn more about key issues affecting the breast cancer community.
- **4.** Sign up for Our National Action Network. We'll send you timely updates about how you can take action.
- **5.** <u>Become an Advocate for Change.</u> Learn more about breast cancer science by attending one of our education and training opportunities, such as the Annual Advocate Leadership Summit or Project LEAD.
- **6.** <u>Support Breast Cancer Research.</u> Learn more about the Artemis Project, NBCC's advocateled, research collaborative, which focuses on stopping people from getting breast cancer and preventing metastasis, so that people stop dying of it.
- **7.** Get Educated About the Issues. Breast cancer is a complex disease. NBCC breaks down the most complicated topics, such as screening, drug approval, and treatments.
- **8.** Make a Donation. Support research, education, and training, and our mission to end breast cancer.

Find out more at <u>www.stopbreastcancer.org</u>



NBCC FACTS

he National Breast Cancer Coalition (NBCC) has a unique history and an unmatched record of accomplishment in breast cancer. Since its inception in 1991, NBCC's mission has been to end breast cancer. NBCC has a long history of taking on big issues, challenging the status quo facing controversy head-on, and achieving success.

NBCC links hundreds of organizations and tens of thousands of individuals from across the country into a dynamic, diverse coalition to achieve the organization's mission to end breast cancer and to give breast cancer a meaningful voice in Washington, D.C. and state capitals, in laboratories and health care institutions, and in local communities everywhere.

NBCC's Key Programs Are Centered on the Following Priorities:

Funding for Innovative Research: NBCC creates new models of research, bringing significant funding to scientists and overseeing how those funds are spent. The organization's advocacy led to the creation of the Department of Defense Breast Cancer Research Program and more than \$3.9 billion of new federal funding for innovative breast cancer research. Trained NBCC advocates participate at all levels to monitor funding and ensure dollars are well spent on meaningful research.

Research Collaborations: NBCC leads collaborations that set priorities and change the systems of research. Through an innovative, mission-driven approach of strategic summits, catalytic workshops, and collaborative efforts—collectively called the Artemis Project®—advocates and scientists work side-by-side to identify and answer the questions vital to ending breast cancer. Our current projects include a collaboration on a preventive breast cancer vaccine and a strategy to understand and address tumor dormancy. Our Clinical Trials Initiative makes certain that trained breast cancer survivors are included in the design, implementation, and accrual of important trials; and that policies encourage access to trials and mandate insurance coverage for participants.

Education and Training: NBCC demanded—and won—a place for advocates wherever decisions are made in breast cancer research and health care. Through innovative training programs such as Project LEAD®, science training for lay advocates, and leadership programs that empower advocates with training in public policy and health care,

NBCC prepares advocates to provide an informed patient perspective in designing research, determining quality care, and other highly specialized areas of breast cancer activism. Programs are offered in-person and online to reach as broad and diverse an audience as possible.

Communications and Public Information: In order to change the conversation in breast cancer from awareness to a focus on ending the disease, NBCC issues annual Progress Reports that summarize the state of breast cancer as well as the status of NBCC's work to end breast cancer. NBCC also keeps a watchful and critical eye on media and publications about breast cancer and offers unbiased analysis of research and health care through media alerts, position papers, and our Beyond the Headlines program.

Coalition Development and Support: NBCC provides resources and support to member organizations nationwide and across the globe through our National Action Network (NAN) and ongoing training of the grassroots network to equip them with current information and materials to share with decision-makers and the general public.

Other Accomplishments Include:

Access to Care: NBCC drafted and fought for 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 thousands of uninsured women.

National Action Plan on Breast Cancer: At NBCC's urging, the Clinton administration created a unique collaboration of government, science, private industry, and consumers. NBCC's President co-chaired the Plan's implementation.

Clinical Trials: NBCC has been engaged as a key partner in numerous, seminal clinical trials, including the pivotal trial of trastuzumab (Herceptin) for HER2 positive breast cancer; the TAILORx trial of the Oncotype DX Recurrence Score; the PALOMA-2 trial palbociclib (IBRANCE) a CDK4/6 inhibitor; and EMBRACA trial of talazoparib (TALZENNA), a PARP inhibitor, among others.

NBCC was recognized as one of the top 25 most influential groups in national health policy in a University of Chicago survey of congressional staffers. NBCC has an "excellent" rating from the American Institute of Philanthropy for effective use of funds raised and is a Better Business Bureau Accredited Charity.



Programs Overview

Transforming Systems & Catalyzing Progress to Achieve Our Mission to End Breast Cancer

Catalytic Research Projects & Collaborations

ARTEMIS Project®

The Artemis Project: NBCC's Artemis Project® is centered around strategic summits, catalytic workshops, and collaborative efforts with a multidisciplinary and diverse group of stakeholders. This advocate-led, innovative approach allows scientists, industry representatives, and regulators to work collaboratively with advocates to develop and implement strategic research plans that could have a significant impact on primary prevention and saving lives. Projects include:

- Artemis Project® for a Preventive Breast Cancer Vaccine: A strategic plan for the development of a preventive vaccine in breast cancer.
- Artemis Project® on the Prevention of Metastasis: Determining the process by which breast cancer spreads and becomes lethal, and how to intervene to stop it.
- Seed Grants for Research: NBCC has awarded seed grants to allow scientists to begin the research required in key areas identified in the collaborative research plans.

Clinical Trials Initiative: NBCC works with industry and the research community on clinical trials that meet the criteria of NBCC's Clinical Trial Project. We involve breast cancer activists in all aspects of clinical trial design, implementation, and oversight. We work to improve access to quality clinical trials and, thus, treatment and care for women with breast cancer and strategies for those at risk.

Education & Training

The Center for NBCC Advocacy Training supplies the education, tools, training, and action that enable breast cancer survivors and other advocates to understand complex medical and scientific information and to take leadership roles in clinical, scientific, funding, and policy decision-making that affects breast cancer. Programs include:

Advocate Leadership Summit: Three days of educational and strategy building sessions to train and empower breast cancer survivors and other advocates by providing information and background about breast cancer as well as the tools and tactics necessary to take a leadership role in breast cancer advocacy.

Project **LEAD**®

- Project LEAD® Institute: Annual intensive sixday course in core science training for advocate leaders to learn the language and concepts of science with a focus on the biology of breast cancer, genetics, epidemiology, research design, and advocacy.
- Advanced Project LEAD®: Ongoing educational and training sessions for advocates who excel in science and have successfully completed Project LEAD®, focusing on enhancing critical thinking and research skills.
- Clinical Trials Project LEAD®: Advanced, intensive training for graduates of Project LEAD® in the key aspects of clinical trial design, implementation, and oversight.
- **Project LEAD® Workshop:** Two-and-one-half-day entry-level course in breast cancer science that teaches how to critically analyze research

and evaluate breast cancer information in the media.

- Continuing Education for Project LEAD® Graduates: Continued scientific education and research involvement, including LEADgrads Online resources, Advanced Topics sessions at various scientific meetings, and LEADcasts online webinars with well-known researchers.
- Online Center for Advocacy Training: NBCC's esteemed training experiences brought directly to advocates in a convenient and understandable digital format.
- **Team Leader Training:** Prepares grassroots leaders to understand the legislative process and to forward NBCC's annual public policy agenda.

Public Policy

Public policy plays a significant role in all aspects of breast cancer. NBCC focuses its public policy advocacy on priorities that will have a major impact on ending breast cancer, including those that will increase funding for meaningful breast cancer research, provide access to high-quality health care and clinical trials, and expand the influence of breast cancer advocates everywhere breast cancer decisions are made.

NBCC hosts a series of Congressional Forums on Capitol Hill designed to educate policymakers on issues vital to the breast cancer community. NBCC provides members of Congress and their staff up-to-date information about breast cancer and reports on research discoveries that affect policy and appropriations. NBCC leadership often testifies before Congressional committees on substantive breast cancer issues.

Grassroots Field Network Development & Support

NBCC provides resources and support to member organizations nationwide and enhances education and training among diverse populations of breast cancer activists.

All organization and individual members of NBCC's National Action Network receive email alerts throughout the year, usually twice each month, with important information and timely actions for their advocacy. NBCC also convenes regular conference calls and webinars for the grassroots field network to provide individualized guidance, informational materials, and peer-to-peer support.

Public Information, Communications & Outreach

NBCC has undertaken an expansive effort to change the conversation around breast cancer to a dialogue about knowing how to end the disease.

- Breast Cancer Information Campaigns:
 - The NBCC website and print and electronic communications help educate the public with facts about breast cancer. NBCC's expert staff analyze research studies and media coverage and present the truth behind the news.
- Global Influence: The NBCC executive team, board of directors, and advocate leadership represent the breast cancer community, advocating on its behalf and serving on scientific, medical, and research bodies at the national and international levels.

Through all of these programs, NBCC supports and facilitates the research needed to end breast cancer, global access to the necessary information and lifesaving interventions, and the influence of leaders everywhere in the strategies to end breast cancer.



Public Policy



2022 Legislative and Public Policy Priorities

Legislative Priorities

PRIORITY #1:

\$150 Million/Level Funding for the Department of Defense (DOD) Breast Cancer Research Program

(BCRP) for FY2023: As a result of NBCC's grassroots advocacy, the DOD BCRP was created in 1992 toeradicate breast cancer 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 which 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 (S. 1312/H.R. 3183): A bill to waive the 24-month waiting period for Medicare and the five-month waiting period for Social Security Disability Insurance benefits foreligible individuals with Metastatic Breast Cancer. This legislation would waive all waiting periods for Medicare and Social Security Disability Insurance (SSDI) benefits based on disability for individuals withmetastatic 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 lobbyingand 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

PRIORITY #1:

Guaranteed Access to Quality Care for All: Ensuring access to quality evidence-based health carehas been a top priority of NBCC for many years. NBCC supports health care access initiatives that expandaccess to Medicare while also offering a private insurance option, automatically enroll individuals who do not have access to other coverage, and provide 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:

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 #3:

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 represent a constituency have a meaningful seat at the table in all levels of health care decision making, which affects their lives.

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 disease; and
- Be knowledgeable, trained, prepared and confident in their ability to participate in the decision-making process of science and medicine.



Breast Cancer Facts and Figures

The National Breast Cancer Coalition (NBCC) is a grassroots organization dedicated to ending breast cancer through action and advocacy. These statistics illustrate the need to stop this deadly disease.

INCIDENCE

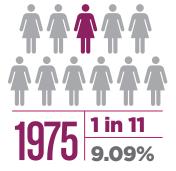
Excluding basal cell and squamous cell skin cancers, breast cancer is the most commonly diagnosed cancer among women in the U.S. In 2022, there will be an estimated **287,850***

new cases of invasive breast cancer diagnosed in women; **2,710*** cases diagnosed in men and an additional **51,400** cases of ductal carcinoma in situ (DCIS)** diagnosis in women. (ACS, 2022)

Lifetime Risk

In the United States, a woman's lifetime risk of being diagnosed with invasive breast cancer has increased since 1975. (ACS, 2022; DeSantis et al., 2021)





Incidence By Age

Older women are much more likely to get invasive breast cancer than younger women. From 2014-2018, the median age of a breast cancer diagnosis was 63 years of age. (NCI, 2022)

MORTALITY



In 2020 there were 684,996 deaths from breast cancer globally. (WHO, 2021) Breast cancer is

the 2nd leading cause of cancer death for women

in the United States, after lung cancer.

In 2022, it is estimated that

43,250 women and 530 men

will die of breast cancer.
(ACS, 2022)

Progress in breast cancer mortality reduction has slowed in recent years. The mortality rate was decreasing by about 1.9% annually between 1998 and 2013. Annual declines have slowed to 1.1% between 2013 and 2019. (ACS, 2022)

While the breast cancer mortality rate has declined, the number of women and men who die each year is rising and will continue to rise as the aging population grows.

Mortality By Age

From 2015-2019, the median age at death from breast cancer was 69 years of age. (NCI, 2022)



Despite a similar incidence, mortality from breast cancer among black women is **41% higher** compared with white women. (ACS, 2022)



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JANUARY 2022

^{*}These statistics do not account for the effect of the COVID-19 pandemic.

^{**}Annual incidence counts of lobular carcinoma in situ are no longer measured following its removal from the 2017 edition of the AJCC breast cancer staging system.



Breast Cancer Facts and Figures

RECURRENCE

An estimated **20%** to **30%** of women diagnosed, treated, and declared free of disease for local or regional invasive breast cancer will have a recurrence. (Saphner et al., 1996; Harris et al., 2000; Colleoni et al., 2016)

PREVALENCE

3.8 million individuals living with a history of breast cancer in the United States.

The number of women living with metastatic breast cancer in the United States:

In 2017-155,000 By 2020-168,292

(Mariotto et al., 2017)

RISK FACTORS

All women are at risk for breast cancer. Only 5-10% of women (5-20% of males) with breast cancer have inherited **a mutation in a known breast cancer gene** (e.g., BRCA1 and BRCA2). The majority of breast cancer cases do not involve these inherited mutations. (ACS, 2017-2018)

Factors that increase a woman's risk of breast cancer include:

- Getting older
- Genetic mutations
- Long menstrual history
- Having dense breasts
- Personal history of breast cancer or certain non-cancerous breast diseases



 Family history of breast or ovarian cancer

(DeSantis et al., 2019)

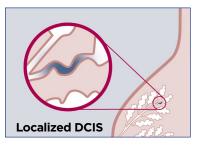
- Previous treatment using radiation therapy
- Never having children
- Being over 30 years at first full-term pregnancy
- Recent use of hormonal contraceptives or high natural levels of sex hormones
- Use of combined postmenopausal hormone replacement therapy
 Being overweight or
 - obese after menopause
 - Not being physically active
 - Drinking alcohol (ACS, 2020, CDC, 2019)

DCIS AND SCREENING

The diagnosis of ductal carcinoma in situ (DCIS) was rare before 1980.

Widespread adoption of screening mammography has led to an **800% increase** in the incidence of DCIS. However, screening has not resulted in a decrease in the rate of lethal disease (i.e., stage IV, metastatic disease) at diagnosis.

Overdiagnosis of breast cancer (i.e., cancer that would never become a problem) is estimated to occur in 22-31% of all screen-detected breast cancers. (Bleyer and Welch, 2012)



TREATMENT

The current methods of treatment in use in the U.S. are:

Surgery (Mastectomy)











DONATE to the National Breast Cancer Coalition Fund

The National Breast Cancer Coalition Fund's mission is to end breast cancer. Every dollar raised is immediately put to work funding scientific collaborations, research, advocacy and science training, and public policy work in Washington, D.C. and state capitals across the country to support NBCC's mission.

Your tax-deductible donation will support NBCC as we:

- Collaborate with scientists to design research and shape clinical trials
- Launch a clinical trial for a breast cancer preventive vaccine
- Learn how to stop breast cancer metastasis from taking lives
- Learn how to prevent the disease from developing
- Train and empower advocates to be effective leaders in breast cancer research and public policy
- Set the national breast cancer research agenda
- Set a public policy agenda focused on our mission to end breast cancer
- Push for access to high-quality health care for all and
- Expand the influence of breast cancer advocates in research, health care and public policy

With a \$1,000 or more gift, you join the President's Council, an exclusive group who receive regular communications directly from NBCC's President on current breast cancer issues, recognition in publications, and invitations to special events.

NBCC meets all 20
Better Business Bureau
Charity Standards,
has received an "A"
rating from Charity
Watch, is listed at the
Gold Standard level
for Guidestar, and is
ranked three stars by
Charity Navigator,
so you can be
assured your money
is well spent.

☐ I want to contribute \$	monthly (Jo	in the President's C	ouncil for \$85 per month)		
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CARD NUMBER	CVC CODE	EXPIRATION DATE	- As a 501(c)(3) charitable		
Yes, please add me to your: Email list to receive newsletters and event invitations			organization, the National Breast Cancer Coalition Fund states that no goods or services were received for your contribution. Your gift is deductible to the extent permitted by federal law.		
National Action Network to receive Action Alerts with information about specific actions I can take to advance NBCC's legislative and public policy priorities					



Although our financial report is always available upon request, some states require us to advise you that a copy of our financial report is also available through their offices. Financial information about the National Breast Cancer Coalition Fund can be obtained by contacting us at National Breast Cancer Coalition, 2001 L Street, NW Suite 500, PMB #50111 Washington, DC 20036, 202-296-7477 or as stated below. Colorado: Colorado residents may obtain copies of registration and financial documents from the office of the Secretary of State, (303) 894-2680, http://www.sos. state.co.us/re: Reg. No. 20023006015. Florida: SC No. CH10468. A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE, WITHIN THE STATE, 1-800-HELP-FLA. Georgia: A full and fair description of the programs and activities of the National Breast Cancer Coalition Fund and its financial statement are available upon request at the address indicated above. Illinois: Contracts and reports regarding the National Breast Cancer Coalition Fund are on file with the Illinois Attorney General. Kansas: The annual financial report for the National Breast Cancer Coalition Fund, Kansas Registration no. 281005-9 for the preceding year is on file with the Secretary of State. Maryland: For the cost of postage and copying, documents and information filed under the Maryland charitable organizations laws can be obtained from the Secretary of State, Charitable Division, State House, Annapolis, MD 21401, (800) 825-4510. Mississippi: The official registration and financial information of the National Breast Cancer Coalition Fund may be obtained from the Mississippi Secretary of State's office by calling 1-888-236-6167. New Jersey: INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION MAY BE OBTAINED FROM THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING 973-504-6215. New York: A copy of the latest annual report can be obtained from the organization or from the Office of the Attorney General by writing the Charities Bureau, 120 Broadway, New York, NY 10271. North Carolina: Financial information about this organization and a copy of its license are available from the State Solicitation Licensing Branch at 1-888-830-4989. Pennsylvania: The official registration and financial information of the National Breast Cancer Coalition Fund may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 1-800-732-0999. Virginia: Financial statements are available from the State Office of Consumer Affairs, P.O. Box 1163, Richmond, VA 23218. Washington: The notice of solicitation required by the Charitable Solicitation Act is on file with the Washington Secretary of State, and information relating to financial affairs of the National Breast Cancer Coalition Fund is available from the Secretary of State, and the toll-free number for Washington residents: 1-800-332-4483. West Virginia: West Virginia residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. REGISTRATION IN THE ABOVE STATES DOES NOT IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION OF THE NATIONAL BREAST CANCER COALITION FUND BY THE STATE.



JOIN US as a member and take action to end breast cancer.

The National Breast Cancer Coalition (NBCC) is a network of hundreds of groups and thousands of grassroots advocates who are racing against the clock to save lives. Our activism has generated more than \$3.9 billion in new federal funding for innovative breast cancer research. NBCC educates thousands of breast cancer advocates to participate in policy and legislative decisions affecting breast cancer research, health care, and public policy. As a member, you will support our aggressive advocacy and lobbying to increase funding for breast cancer research and guaranteed access to quality health care and treatment for all.

As a member, you can:

- Apply for limited spots at our annual Project LEAD training
- Apply for scholarships to educational and training events
- Access special webinars and training videos
- Submit ideas for NBCC's annual legislative and policy priorities
- Participate in NBCC's annual Lobby Day

FIRST NAME	LASTN	LAST NAME		
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	letwork to receive Action Alerts tions I can take to advance NBC rities			

We combine the power of grassroots advocacy, education, policy, and research to unite around one goal: ending breast cancer.

Makes checks payable to:

National Breast Cancer Coalition 2001 L Street, NW Suite 500, PMB #50111 Washington, DC 20036

The National Breast Cancer Coalition lobbies aggressively to increase funding for breast cancer research and is designated a 501(c)(4) organization. Contributions to NBCC are therefore not tax-deductible.

To conduct lobbying and educational efforts, NBCC is composed of two organizational arms: The National Breast Cancer Coalition is a 501(c)(4) corporation whose purpose is to lobby Congress and the states for improved public policies to move toward the eradication of breast cancer. The National Breast Cancer Coalition Fund is a 501(c)(3) corporation that supports the educational efforts of NBCC and advocates through activities that address administrative agencies, scientists, and health care professionals. Together, the two arms of NBCC issue a call to action by offering diverse and substantive activities, programs, training, and events designed to educate and empower individuals to fight effectively to end this disease.



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