

**action** **annual report** **advocacy** **community LEADERSHIP**

**2018**

**impact**

training  
effective  
education  
partnerships

National Breast Cancer Coalition

intelligent  
innovative  
rele**bold**nergized  
NBCC  
effective  
passionate  
determined

## A Message from The President

**Relentless. Passionate. Determined. Energized. Innovative. Bold.** All these words describe NBCC and our advocacy. But one word best describes our impact — **Effective.** We get things done.

For nearly 30 years, NBCC has led the effort to end breast cancer through action and advocacy. Our unique approach and advocate expertise, our focus and tenacity, has resulted in significant progress through the years.

We have asked the difficult questions, challenged the status quo, and forced change. After decades of work at the national, state, and local levels, NBCC is the undisputed leader in identifying and directing the policy, scientific, clinical, and research tools needed to end breast cancer.

As you'll see in the pages ahead, in 2018, NBCC continued to build and strengthen some of our hallmark programs. From our intensive advocacy training programs and focused legislative goals, to our unique scientific and research undertakings like the Artemis Project and DNA.Land, we continue to expand our audience and increase our impact.

At NBCC, we will do whatever it takes to end breast cancer. Whether this means taking on the status quo in questioning long-held perceptions, we go where the science leads us - not where public opinion, headlines, or hype do. We're not afraid. Even if it's not popular.

As we fight this battle, we face continued obstacles, but we won't be deterred. In the following pages, you can read more about our successes, and our plans to build on them.

We need your continued support, advocacy, and commitment if we are to reach our ambitious but achievable goal — a world without breast cancer.



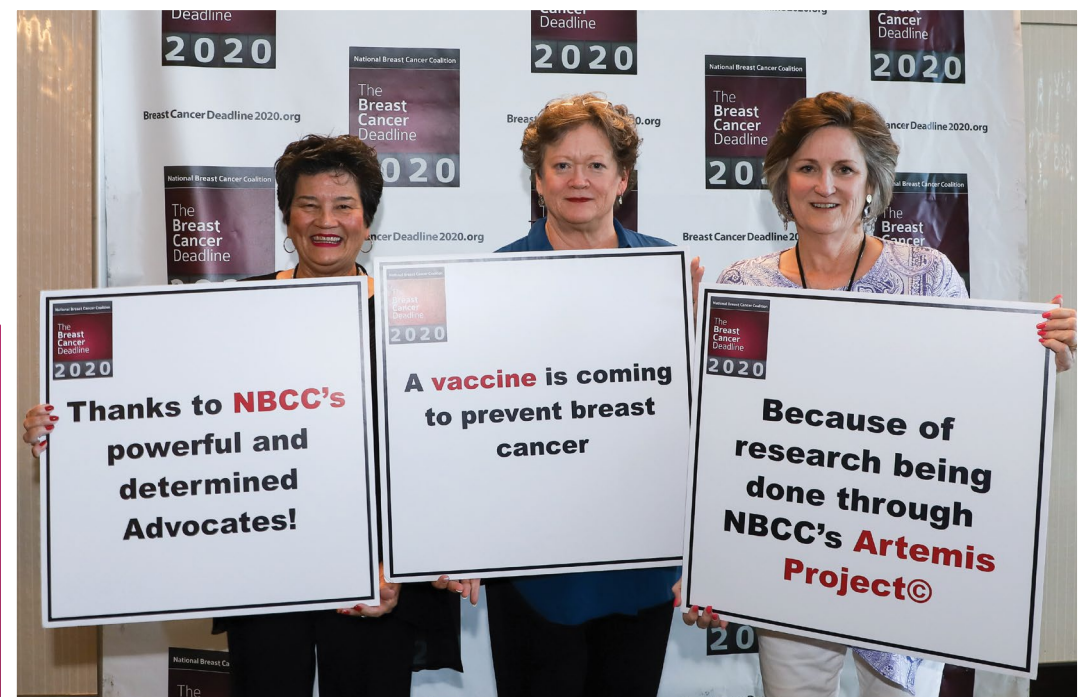
Fran Visco  
President, National Breast Cancer Coalition

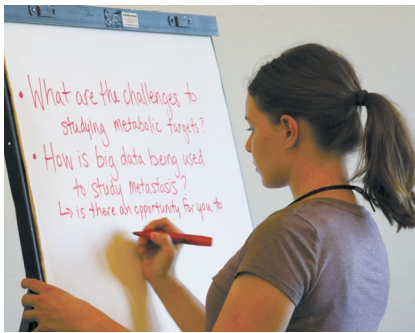
2018

## The Advocate Voice: Training Advocate Leaders in Science and Policy

NBCC provides the highest quality advocacy training, tools, and education to enable breast cancer survivors and other advocates to take leadership roles in clinical and scientific decision making that affects breast cancer research, healthcare, and public policy.

Understanding scientific concepts and processes at a level to make a real difference takes a great deal of work, dedication, training, and time. NBCC advocates are willing to make that commitment and acquire the education and skills they need through NBCC's **Center for Advocacy Training**, the umbrella program for our education and training curriculum. We give advocates and the public the needed tools to understand and translate complex medical information and to partner with scientists in designing and conducting research, including clinical trials.





## Advocate Leadership Summit

An energized, committed and passionate group of NBCC leaders came together for our 2018 **Advocate Leadership Summit** in Arlington, VA, on April 28 -30 for networking, training and education in research and policy.

The preconference program began with a Project LEAD® Workshop: “Early Dissemination of Cells That Become Lethal Metastasis.” The Summit featured fascinating plenary sessions on the progress of the Artemis Project, advocacy in the current political climate, the ethical issues surrounding cancer treatments, as well as an armchair discussion on the impact of DoD-funded research, and a Q&A session with Dr. Dennis Slamon. There were nine skill-building workshops on topics such as how to participate effectively in a scientific peer review and ramp up critical appraisal skills, to policies affecting access to health care, understanding genomics and breast cancer, and the NBCC initiative Campaign Vote Breast Cancer.

In addition to a substantive program, the Summit provided plenty of opportunities for networking and connecting with advocates from across the country. Advocates were also able to interact directly with the speakers during the Advocate-Speaker Meet Ups. These meet-ups provided opportunities for dialogue with speakers in a smaller, more casual setting.

Advocates were enthusiastic with the Summit programming. They valued the variety of the skill-building workshops, as well as the opportunity to converse with scientists in an intimate setting. The 2018 Summit, with its focus on bold advocacy, made many attendees eager for opportunities to put the skills they learned into practice.





## Project LEAD® Institute

**Project LEAD® Institute** educates advocates to understand complex medical information, the nuances of research methodology and the unique role advocates play in influencing the research agenda. Advocates learn about cancer biology, genetics, DNA, RNA, proteins, epidemiology, clinical trial research design and much more. This world renowned six-day program enables attendees to develop skills in critical appraisal so that they are able to ask relevant questions and explain the significance of medical and health information to their communities.

NBCC hosted another successful Project LEAD® Institute in La Jolla, California July 22-27. A diverse class of 43 advocates gathered for a week of intense, dedicated study. The class included participants from 18 different states and international advocate leaders from Armenia, Australia, and Mexico.

Graduates of the Project LEAD® Institute play critical roles in programs such as the Department of Defense (DoD) Breast Cancer Research Program (BCRP), clinical trials and research programs domestically and abroad.

## Advanced Project LEAD®

The **Advanced Project LEAD®** program further trains LEAD graduates who have a deep interest in and propensity for taking leadership roles in breast cancer research advocacy as NBCC representatives. In 2018, Advanced LEAD® advocates engaged in an in-depth, intensive program over two days, that delved into how research and evidence are used in evaluating drug and device effectiveness in the treatment of breast cancer. Advocates also got a closer look at FDA approval processes and examined case studies about how genetic tests are evaluated. The program culminated in the development of a policy paper outline addressing how evidence is used in developing the statutory language found in regulations and other legislation.

In the fall, advocates completed the Advanced Project LEAD® proposal project, the development of a scientific proposal and presentation. These advocates will join the class of other Advanced LEAD® advocates to participate with NBCC on important research projects.

## Continuing Education for Project LEAD® Graduates

**Project LEAD®** graduates continue their science education through the Project LEAD® Continuing Education Program.

**LEADcasts** provide access to online webinars that are presented by **Project LEAD®** faculty and other notable experts on current topics in breast cancer research. These webinars take place several times a year and are open to all advocates who have graduated from a **Project LEAD®** course. Below is a list of highlights from the 2018 LEADcasts:

- ***Immunotherapy and CAR-T: A Decade of Progress in the Clinic***, Premal Patel, MD, PhD, Senior Vice President, Early Clinical Development, Juno Therapeutics, Inc.
- ***Tumor Draining Lymph Nodes and Biologic Behavior***, Peter Lee, MD, Billy and Audrey L. Wilder Endowed Professor and Chair Cancer Immunotherapeutics & Tumor Immunology (CITI), City of Hope Comprehensive Cancer Center
- ***Surrogate Endpoints in Clinical Trials***, Vinay Prasad, MD, MPH, Associate Professor of Medicine at Oregon Health and Science University
- ***The Normal Breast and Its Development***, Susan Love, MD, Dr. Susan Love Research Foundation
- ***The Immune System and Tumor Dormancy: Can we prevent lethal disease?***, Cyrus Ghajar, PhD, Fred Hutchinson Cancer Research Center

In December, 75 **Project LEAD®** graduates gathered prior to the San Antonio Breast Cancer Symposium to participate in NBCC's annual Project LEAD® Advanced Topics

Session. This year's program featured a presentation by Dr. Keith Knutson of the Mayo Clinic, who discussed his work on breast cancer vaccine trials – both the progress on a preventative vaccine and research on vaccines that could prevent breast cancer recurrence. Attendees also heard a presentation from Dr. Nicholas McAndrew of the UCLA David Geffen School of Medicine on the science behind, and his research into, CDK 4/6 inhibitors.

## Online Center for Advocacy Training

NBCC's **Online Advocacy Training Center** is a resource for advocates around the world to hear presentations from leaders in the breast cancer field, including presenters from NBCC's Project LEAD® courses, Advanced Topics sessions, and Advocacy Summits. In 2018, NBCC expanded this resource to include more videos and LEADcasts so advocates could access these thought-provoking and educational conversations.

## Team Leader Training

In March 2018, NBCC selected 22 breast cancer advocates from around the country to come to Washington, DC for an intensive training and development in grassroots advocacy, the federal legislative process, the NBCC legislative and public policy agenda, and lobbying techniques. Following training and preparation, advocates participated in Capitol Hill meetings with Congressional staff to discuss NBCC's legislative and public policy agenda.

## Accelerating Innovation in Research

### The Artemis Project®

NBCC's research work focuses on the **Artemis Project®**, an advocate-led, innovative, mission driven approach of strategic summits, catalytic workshops, action plans and collaborative efforts of various stakeholders, focusing on two areas: Primary Prevention and Prevention of Metastasis.

In March, NBCC held annual meetings on both topics. These meetings included 35 participants comprised of advocates and scientists with expertise ranging from immunology, biophysics, and genetics, to molecular biology, and clinical oncology.



### Primary Prevention

Important progress has been made in the critical activities needed to develop and test a preventive vaccine. In 2018, the vaccine development plan was presented to the FDA and received positive feedback. The project now moves to the next critical steps leading to a Phase I safety trial. Overall, the Artemis Project continues to advance the concept that a breast cancer prevention vaccine is feasible, and its development continues to be pioneered by Artemis.

### Prevention of Metastasis

At the 2018 meeting, the group discussed how data would be best used to identify targets for preventing lethal disease and risk reduction. Participants in the Artemis Project are continuously reevaluating the state of the sciences to ensure that alternatives, or additional opportunities to prevent breast cancer and end deaths are being considered, and appropriately incorporated into the goals of the Artemis Project. To this end, the participants discussed the following topics during the meeting:

- Designing an Anti-Metastasis Clinical Trial
- Grand-Challenge: Disseminated Tumor Cells In Situ
- Vaccine Against New-Antigens to Prevent Metastasis



# influence

## DNA.Land

**DNA.Land** asks individuals to submit results of genetic tests done through various companies that perform genome testing on saliva and answer a clinical questionnaire specific to breast cancer. The goal is to develop a database resource to help determine why some individuals with breast cancer recur. By the end of 2018, over 25,000 people had completed the clinical questionnaire.

A summary report from the 2018 Artemis Project® meetings is available online:

<http://www.breastcancerdeadline2020.org/about-the-deadline/artemis-project.html>

## Advocate Influence

National Breast Cancer Coalition Board Members, Project LEAD® graduates, advocates and members continue to be active on national and international committees dedicated to furthering breast cancer research. Highlights include the Department of Defense Breast Cancer Research Program (DOD BCRP) Integration Panel, Love/Avon Army of Women Steering Committee, Advisory Council of the Agency for Healthcare Research and Quality, and a number of steering committees and data safety monitoring committees of clinical trials for new therapies. And, NBCC President, Fran Visco, served as a member of Translational Research in Oncology's (TRIO) Board of Directors and also on the Governance Board for



the Institute for Clinical and Economic Review. For a full list, please visit [www.deadline2020.org/NationalCommittees](http://www.deadline2020.org/NationalCommittees).

Our leaders and advocates continue to push for partnerships and collaboration, especially when it comes to clinical trial design and oversight. Over the past 12 months, the results of two important clinical trials were reported and NBCC was a collaborator in both of them. NBCC advocates gave input into trial design, sat on steering committees and had the first ever lay advocate participate as a member of a data safety monitoring board.



## Public Policy

Our advocacy efforts have transformed the way breast cancer is seen and heard and have made NBCC one of the most respected organizations on Capitol Hill. With our annual lobby days and national action network, NBCC called on its network of hundreds of groups and tens of thousands of grassroots advocates to focus on NBCC's legislative and public policy priorities.

Each year, NBCC's Board of Directors establish NBCC's legislative and public policy priorities.

Two of NBCC's top 2018 legislative and public policy priorities were:

### DoD Breast Cancer Research Program

The **Department of Defense Breast Cancer Research Program** (DOD BCRP) was established as a direct result of NBCC's leadership in the breast cancer community. The annual Congressional renewal process is grueling and complex, but NBCC's efforts ensure annual funding for the program remains a top priority. In 2018, NBCC effectively advocated for another \$130 million in breast cancer research from the DOD BCRP.

One of the reasons NBCC values the DOD BCRP is because it accepts and reviews innovative and even unconventional proposals that may provide important breast cancer research breakthroughs. To date, funding totals more than \$3.6 billion for research. NBCC and its advocates involvement with the DOD BCRP is also about participation, which is a crucial piece of the program. NBCC breast cancer advocates are members and participate in peer and programmatic review.

The full list of NBCC's 2018 and current priorities can be found at [breastcancerdeadline2020.org](https://breastcancerdeadline2020.org).

### H.R. 6114 – Metastatic Breast Cancer Access to Care Act

NBCC continued to focus efforts on protecting quality care for breast cancer patients. H.R. 6114, one of NBCC's top **legislative priorities**, is a bill to waive the waiting periods for Medicare and Social Security Disability Insurance for eligible individuals diagnosed with metastatic breast cancer. The legislation was introduced in June and, thanks to the amazing work by NBCC advocates, ended the 115th Congress with 96 cosponsors.

## End Breast Cancer: Vote!

In 2018, NBCC launched the **End Breast Cancer: Vote!** campaign. The campaign asked everyone who cares about breast cancer policy to vote in the mid-term elections and ask their elected officials to support NBCC's platform. Components included NBCC's public policy platform, a voter pledge form, and a toolkit for advocates. NBCC used a microsite, social media posts and ads to publicize the campaign, NBCC's public policy platform and encourage candidates to sign on to support our platform.

## National Action Network

Our grassroots leadership and **National Action Network** are key components of NBCC's advocacy success. Made up of organizations and individuals across the country, this far-reaching grassroots network continues to empower women and men who share a sense of urgency about ending breast cancer. NBCC educates, informs and energizes this network throughout the year.

NBCC's Annual Lobby Day was held May 1, where over 200 meetings occurred with members and congressional staff on Capitol Hill. Over 50 lobby day meetings were held in March as part of Team Leader Training. We emailed action alerts to our network asking advocates to contact specific legislators via phone, email, Facebook and Twitter. Additionally, NBCC field staff hosted leadership strategy conference calls each month.



# Outreach and Media

NBCC's website continues to be a unique resource for newly diagnosed women and their families, as well as others interested in patient-centered, evidence-based information. It is the place for breast cancer patients to get the full story on major controversies in breast cancer. The website provides a variety of thoughtful and informative resources that explain NBCC's position and encourages women to learn the truth about breast cancer in order to make informed decisions regarding their health care.

NBCC maintains an active social media presence to communicate directly with our audience. Sites such as Facebook, Twitter and YouTube allow NBCC to provide important information to new and existing audiences. This continues to be an evolving area of importance to engage advocates and the general public about NBCC priorities.

International media outlets such as the New York Times, CNN, NPR, and USA Today have contacted NBCC for statements and reactions on important developments in breast cancer

and health care. In September, *The New York Times* published a letter to the editor from NBCC President Fran Visco entitled, "Top Cancer Researcher Fails to Disclose Financial Ties in Major Research Journals" in response to their article about a well-known oncologist and researcher who failed to disclose millions of dollars in payments from pharmaceutical companies.

In December, The Cancer Letter published a guest editorial written by Fran, where she discussed recent news in the breast cancer research world and highlighted the role NBCC advocates play in addressing these issues. Trained, educated advocates need to shine a light on the problems that impede progress and they must figure out the solutions. They should be setting the research agenda, collaborating on research generation and conduct, and helping set rules to foster transparency and eliminate conflicts of interest which threaten further progress toward our mission of ending breast cancer.

## Other Media highlights include:

- Statements written on the TAILORx Trial results, Direct to Consumer Genetic Testing and H.R. 6114 Metastatic Breast Cancer Access to Care Act
- NBCC and the LA Cabaret event were mentioned in outlets including People, US Magazine, Daily Mail, Access Online, Entertainment Today and Orlando Sentinel
- NBCC was mentioned in a story broadcast by ABC-WUSA Channel 9, Swim Marathon to fight Breast Cancer
- NBCC President Fran Visco was quoted in an article in US Army Magazine, Investing for Breakthroughs



# events

## 2018 Events

### Les Girls

NBCC's 18th annual **Les Girls Cabaret** was held in October at the Avalon Theater in Hollywood. Every year the event captivates attendees with an unforgettable evening of laughter and song. We honored Dr. Armando Guiliano, the Co-Director of the Saul and Joyce Brandman Breast Center at Cedars-Sinai with the 2018 Les Girls Leadership Award, for his dedication to saving lives and commitment to breast cancer. The award was presented by Julia Louis-Dreyfus. Our spectacular celebrity entertainers such as Sharon Lawrence, Lea Thompson and Steven Weber performed and title sponsor is Clinical helped raise over \$400,000 for NBCC's program and important work.



Laura Avril and Marylinn Minor were presented with awards by our gracious host Tamara Tunie. Guests enjoyed an incredible performance by We' McDonald, The Voice Season 11, contestant.



### NYC Women with Balls®

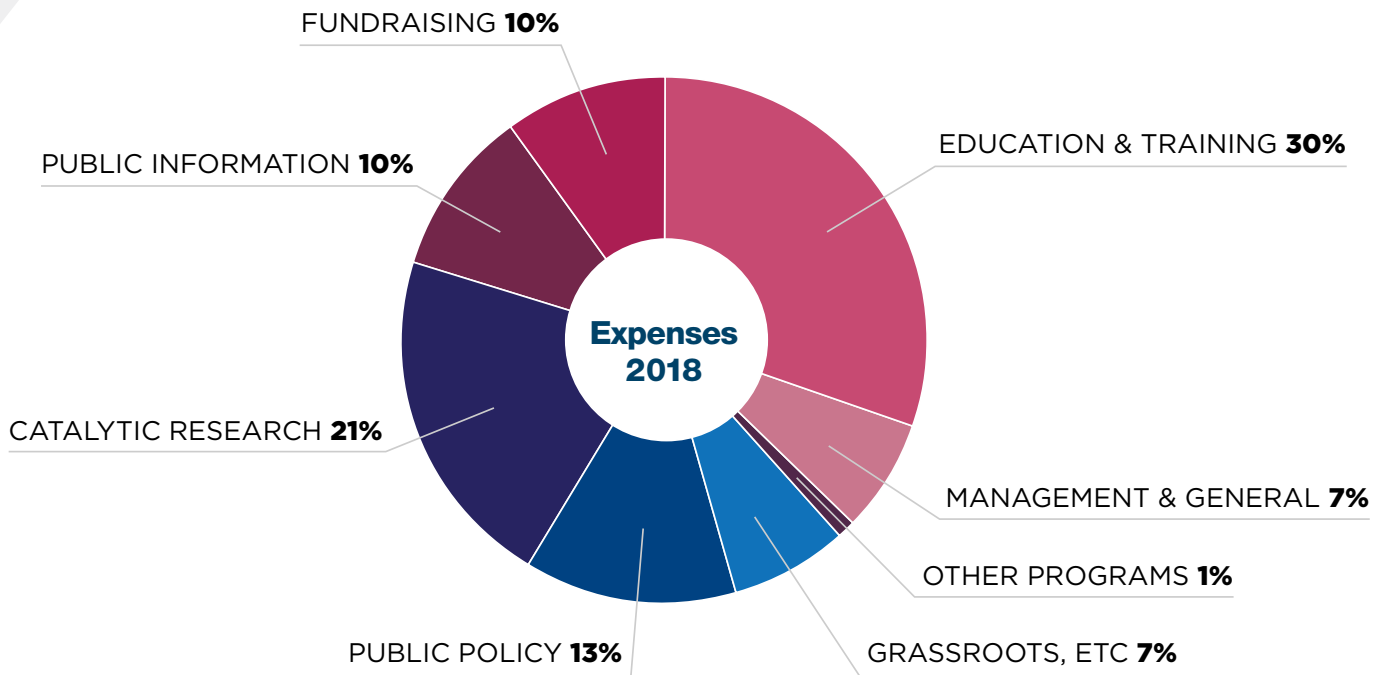
The second annual NYC **Women with Balls®** bowling fundraiser was held at the Bowlmor Lanes in Times Square in May, hosted by Liane Martins Linder, Chairman of NBCC's Board of Trustees. The event brought together like-minded, compassionate and energetic women and men to raise money, bowl and have fun — all for the mission of ending breast cancer.

### New York Gala

NBCC's 23rd **New York Gala** raised over \$1 million. The event co-chairs were Stephanie Disegni, President and CEO, Longchamp USA, Sharon Nelles, Partner, Sullivan & Cromwell, and Debra Perelman, President and CEO, Revlon, Inc. We were very proud to honor an NBCC longtime friend and supporter Mark J. Alles, Chairman and CEO, Celgene. A highlight of the Gala was hearing from our Grassroots Advocacy Award honorees. Our 2018 recipients



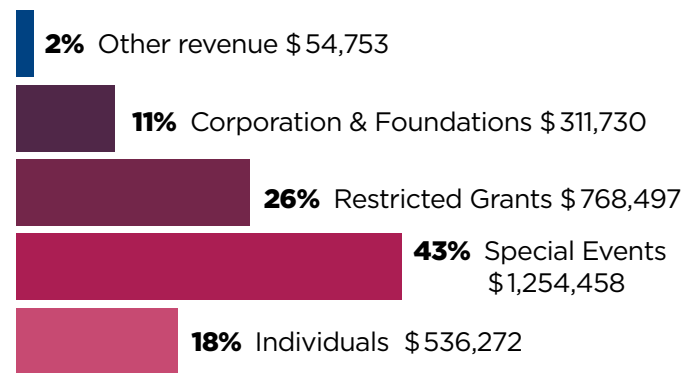
# Your Dollars at Work



## Assets 2018

Cash & Cash Equivalents	\$ 770,246
Accounts Receivables	\$ 895,564
Prepaid Expenses	\$ 102,467
Net Property & Equipment	\$ 184,781
Deposits	\$ 57,134
<b>TOTAL ASSETS</b>	<b>\$ 2,061,326</b>
<b>LIABILITIES</b>	<b>\$ 429,177</b>
<b>TOTAL NET ASSETS</b>	<b>\$ 1,632,149</b>
<b>TOTAL LIABILITIES &amp; ASSETS</b>	<b>\$ 2,061,326</b>

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We have done our best to review these lists. If anything appears incorrect, please accept our apologies and contact NBCC's Development Office at 202-973-0573 or [info@breastcancerdeadline2020.org](mailto:info@breastcancerdeadline2020.org).



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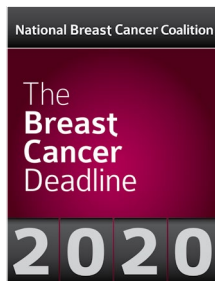
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## **National Breast Cancer Coalition**

1010 Vermont Ave., NW, Suite 900

Washington, DC 20005

**[BreastCancerDeadline2020.org](http://BreastCancerDeadline2020.org)**

The **National Breast Cancer Coalition Fund** is a 501 (c)(3) entity that designs and runs programs to educate, train, and inform advocates, policy makers, scientists, providers, and the public about science, health care and advocacy. The Fund collaborates with the research community on innovative research, effects change in the health care system to advance access to quality health care for all, and gives a powerful, effective voice to breast cancer advocates everywhere.

The **National Breast Cancer Coalition** is a 501 (c)(4) organization that designs and works to enact legislation, policy, and regulation to end breast cancer. The Coalition lobbies through its grassroots network for increased funding for innovative research, a seat at the table to oversee how those funds are spent, and public policies to expand access to quality health care for all.