



## Advocacy in Action





# A MESSAGE FROM THE PRESIDENT

Looking back at 2019 and assessing the National Breast Cancer Coalition's (NBCC's) work allowed me a moment of respite from an all-consuming pandemic. Not that dealing with the impact of a lethal disease is at all comforting. But breast cancer patients and survivors live with uncertainty every day. What is the best treatment for me? Do I have to worry about a recurrence? Will my daughter or mother be diagnosed? Will my insurance cover any costs? What can I do? Is there hope for a solution in my lifetime?

For NBCC advocates, it's the challenge of finding answers and solutions to the uncertainty that drives us. It requires us to look at what we know, what we can change, and how to impose boundaries around the uncertainty. How to break through those boundaries. And that is what NBCC does — whether it's through the ARTEMIS Project® where we're searching for a vaccine to prevent breast cancer or figuring out how to stop metastasis, or through Project LEAD® where advocates learn to participate at all levels of breast cancer decision making. We bring together many voices and perspectives into one meaningful agenda and take it to Capitol Hill and the White House. By empowering ourselves, boldly advocating, and challenging the status quo, NBCC is forcing change.

So, while no one knows the extent to which this pandemic will change our world, one thing is certain — NBCC's dedication and commitment to saving lives and ending breast cancer is steadfast. That will never change.

Thank you for being part of our mission to end breast cancer — for all of us and for future generations.



Frances M. Visco

President, National Breast Cancer Coalition

# RESEARCH

## **ARTEMIS Project®**

NBCC's ARTEMIS Project®, an advocate-led research collaboration, brings together various stakeholders in an innovative, mission-driven approach that includes strategic summits, catalytic workshops, and research action plans. Artemis has two areas of focus: Primary Prevention — how to stop women and men from getting breast cancer — and Prevention of Metastasis — how to stop breast cancer from becoming lethal.

Each year, we host a meeting of Artemis participants to report on accomplishments and develop plans for the next 12-18 months. Throughout the year, participants move action plans forward and engage in webinars and conference calls to refine plans and provide additional input.

## **Prevention of Metastasis**

At the 2019 meeting, a subgroup looked specifically at the technology needed to help answer tumor dormancy issues. They addressed questions, such as whether any existing technology could provide a real-time view of what happens during the metastasis process? Also, if that technology doesn't exist yet, could it be developed? The outcome led to the development of a plan to leverage innovative technology to “see” the process of metastasis and how to intervene.

## **Primary Prevention**

### **Vaccine**

Plans to finalize the Investigational New Drug application (IND) and the Phase 2 clinical trial were discussed, and a Vaccine Project Manager was contracted to work with the vaccine team to advance the Phase I trial.

### **Other Prevention Approaches**

ARTEMIS participants continue to discuss other research topics in the area of primary prevention, such as exploring aspects of the microbiome and risk stratification.



## Clinical Trials

In 2019, NBCC began its collaboration with Translational Research In Oncology (TRIO) and Novartis on a clinical trial of CDK4/6 inhibitors in early high-risk HR+/HER2- breast cancer, the NATALEE trial. NBCC advocates have been working closely with TRIO as an advocate partner to support this trial. Our advocates serve on the clinical trial steering committee, the data safety monitoring board, and the translational research committee.

## DNA.Land

In 2017, the DNA.Land project was launched asking 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 breast cancers recur. Over 30,000 people completed the clinical questionnaire. In 2019, the databases were delivered to NBCC and we are convening an advisory group to guide the development of policies and procedures for data sharing and management.







## EDUCATION AND TRAINING

### Team Leader Training

In March 2019, NBCC brought selected breast cancer advocates from around the country to Washington, DC for 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, activists spread across Capitol Hill meeting with Senators and Representatives or their staff members to discuss and forward NBCC's legislative and public policy agenda. NBCC's trained Team Leaders also led state delegation visits on Capitol Hill during our annual membership lobby day. Additionally, NBCC Field staff hosted monthly leadership strategy conference calls.

### Advocate Leadership Summit

An energized, committed, and passionate group of more than 130 NBCC leaders attended our 2019 Advocate Leadership Summit in Arlington, VA in late April. The Summit was praised as “the best ever” by participants. Thought-provoking plenary sessions followed

on topics, such as “Conflicts of Interest and Their Impact on Breast Cancer Research,” “The Science of Advocacy,”

as well as updates on the progress of the ARTEMIS Project, and conversations about navigating health care policy in the political environment. There were also eight





skill-building workshops on varied topics, such as disparities in breast cancer, informed consent in clinical research, clinical trial design, and the value of transparency in cancer drug development.

## **Breast Cancer Caucus**

NBCC developed the Breast Cancer Caucus, a public policy organizing and advocacy effort around presidential elections. Each presidential election cycle, NBCC conducts a campaign to educate the candidates about the meaningful public policy approaches necessary to end breast cancer and to give them an opportunity to show their support for our mission. We inform the public about where the candidates stand on NBCC's agenda.

In 2019, all of the Democratic candidates and one Republican candidate, endorsed the NBCC policy platform that details the actions they will take on related public policy priorities. NBCC activists intend to hold candidates to their promises, and we are once again ready to push for the initiatives needed to achieve our mission to end breast cancer.





## Project LEAD®

NBCC hosted another successful Project LEAD Institute in La Jolla, California in July, 2019. With a diverse class of 58 advocates, 2019 had one of the largest classes ever — a 38% increase over 2018. Attendees gathered for a week of intense, dedicated study. The 2019 class included participants from 21 different states, the District of Columbia, Puerto Rico, Canada, and Australia.

Throughout the year, NBCC offered Project LEAD graduates continuing education through online webcasts, conference calls, training webinars, regular updates, and an annual meeting at NBCC's Advocate Leadership Summit.

## Project LEAD Grant

In 2019, NBCC received a two-year Eugene Washington Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI) to expand the capacity of Project LEAD's virtual training for advocates around clinical trial methodology, comparative effectiveness research (CER), and PCOR.

## Webinars

As part of its education and training programs, NBCC conducted several webinars in 2019, on topics, such as "Clinical Trials — Designs, Methodology, and Key Issues for Research Advocates" "Vaccines for Breast Cancer — Where Are We in 2019?" and "Dissecting the Tissue Specificity of Cancer Drivers."





# PUBLIC POLICY

The National Breast Cancer Coalition Board of Directors establishes NBCC's legislative and public policy priorities. Each year, issues are brought to the attention of NBCC staff, who conduct research and prepare background information for the Board to review. At the January Board meeting, the members voted on the top legislative priorities. NBCC made significant progress on the 2019 priorities.

## DoD Breast Cancer Research Program

In 1992, the Department of Defense Breast Cancer Research Program (DOD BCRP) started as a result of NBCC's campaign to increase federal appropriations for breast cancer research. The program remains a top priority for NBCC. Thanks to the hard work of NBCC advocates, Congress appropriated \$150 million for FY 2020, an increase from \$130 million in FY 2019.



## Metastatic Breast Cancer Access to Care Act

NBCC's priority legislation (S. 1374/H.R. 2178) The Metastatic Breast Cancer Access to Care Act was reintroduced, and our advocates were responsible for obtaining strong bi-partisan support. By the end of 2019, NBCC had secured 131 cosponsors in the House and 13 in the Senate.

## Annual Membership Lobby Day

During our annual membership lobby day in April, NBCC advocates held more than 300 meetings with their members of Congress on Capitol Hill. Back in home districts, advocates attended town halls, and published letters to the editor in their local papers to advocate for NBCC's priorities.



## 2019 EVENTS

### NBCC's 19th Annual Les Girls

Les Girls Cabaret was held in October at the Avalon Theater in Hollywood. The evening featured an all-star lineup of performers, capped by an unforgettable performance by Carole King.



### NBCC's 24th New York Gala

Our New York Gala honored two breast cancer advocates, Dale Eastman and Valencia Robinson, as well as Devika Bulchandani, president, McCann New York, for their ongoing work to help NBCC. Joey McIntyre provided the entertainment, performing several songs for the crowd.





## And More...

The third annual **Women with Balls**® NYC and the 14th annual Washington, DC events brought together like-minded, compassionate, and energetic supporters to bowl and raise money for a great cause.



Hauser & Wirth hosted an **evening of art** to benefit NBCC. The evening featured a private view of the Philip Guston exhibition, and a presentation by the artist's daughter, Musa Mayer. NBCC was the beneficiary of the West Coast's largest pro **women's**

## squash doubles event.

Held at the prestigious Jonathan Club, the event was a competitive draw featuring world class athletes and a Pro-Am draw.





## OUTREACH

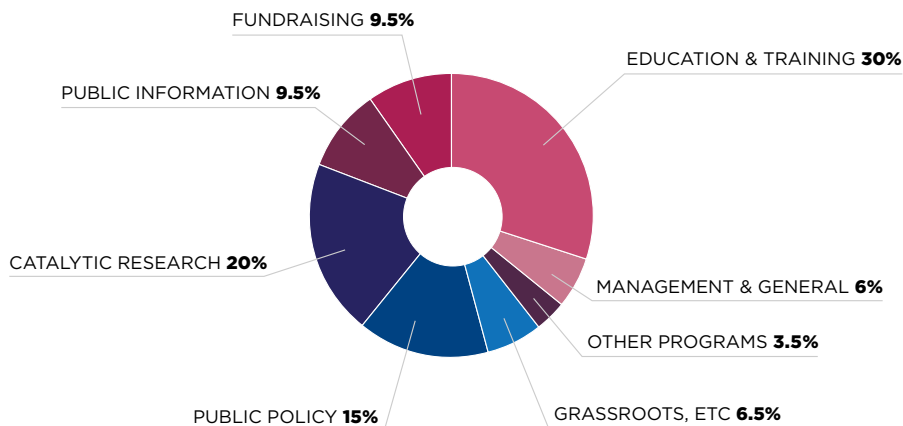
NBCC either presented at or attended a number of national meetings on the issue of clinical trials research, patient advocate involvement in clinical trials, and Deadline 2020 research efforts. These included the National Cancer Institute, the Integration Panel of the Department of Defense Breast Cancer Research Program, and the San Antonio Breast Cancer Symposium.

NBCC, Fran Visco, and advocates continued to comment on breast cancer news and health care policy with statements appearing in news outlets such as *USA Today*, *StatNews*, *Scienceblog*, and *HeathNewsReview*.



# YOUR DOLLARS AT WORK

**2019 Expenses \$3,574,356\***

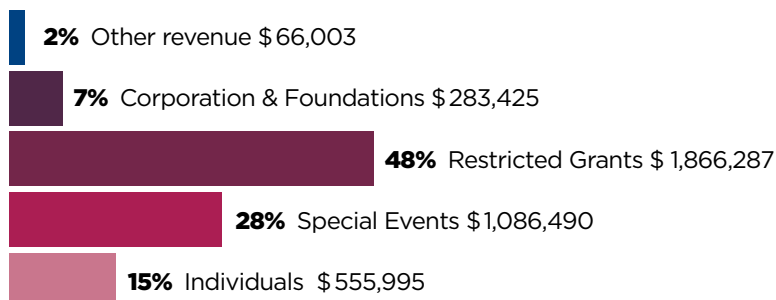


**Note:** Pie-chart reflects expenses of \$3,136,593 — It does not include event related direct benefits to donors \$437,763.

## Assets 2019

Cash & Cash Equivalents	\$1,222,922
Accounts Receivables	\$ 559,327
Prepaid Expenses	\$157,025
Net Property & Equipment	\$175,768
Deposits	\$ 57,134
<b>TOTAL ASSETS</b>	<b>\$2,223,139</b>
<b>LIABILITIES</b>	<b>\$ 307,146</b>
<b>TOTAL NET ASSETS</b>	<b>\$1,915,993</b>
<b>TOTAL LIABILITIES &amp; ASSETS</b>	<b>\$2,223,139</b>

## 2019 Public Support & Other Revenue \$3,858,200\*



\*Total Expense and Total Revenue include event costs that are direct benefits to donors, \$437,763.



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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.

## National Breast Cancer Coalition

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