

2017 NATIONAL BREAST CANCER COALITION ANNUAL REPORT





A MESSAGE FROM THE PRESIDENT

Thanks to your support, in 2017 we advanced our work toward Breast Cancer Deadline 2020® and our mission to end breast cancer.

Once again, we mobilized our National Action Network to ensure the preservation of the Department of Defense Breast Cancer Research Program (DoD BCRP). In 1992, the DoD Breast Cancer Research Program 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, more than \$3.3 billion has been funded for the worldwide research community since its inception.

Ensuring access to affordable and quality healthcare for women and men with and at risk of breast cancer, has long been one of NBCC's top priorities. NBCC advocates worked in collaboration with many other groups, to fight attempts to repeal the Affordable Care Act in 2017. NBCC's network stepped up and its voice was essential in the strong advocacy that ultimately defeated Congressional action to undermine the ACA.

We continued to educate advocates on the science of breast cancer through our highly acclaimed **Project LEAD**® Institute. We also hosted a second pilot program for our new Advanced LEAD science training. NBCC has spent years honing our education and training programs so that there is a network of advocates — women and men around the world — who understand the science, work alongside researchers, and bring their critical perspectives to bear in order to make the right research happen. And our trainings makes it possible for advocates to communicate complex scientific and medical information to the public. Graduates from **Project LEAD**® courses are the most well-trained and influential in breast cancer advocacy.

We helped many women and men across the country hone their skills in public policy and health care through our Leadership Summit, online education programs and Team Leader Training. We launched a partnership with DNA.Land to develop a large scale resource for studying breast cancer genomics. We also moved forward with our work on a preventive vaccine and moved closer to understanding how to prevent metastasis through our Artemis Project®.

As you read our 2017 annual report, you will learn more about the work we accomplished together. But we are not finished yet. With your continued support, we can achieve a world without breast cancer. How do we know we can do it? Because since its inception, NBCC has been the undeniable leader in identifying and marshalling the policy, scientific, clinical and research tools needed to end breast cancer.



Fran Visco
President, National Breast Cancer Coalition

THE ADVOCATE VOICE

Training Advocate Leaders in Science and Policy

NBCC advocates have no agenda other than to end breast cancer and save lives. That is one reason it is vital that their voices are at all tables where decisions are made in breast cancer research, health care and public policy. But those voices must be informed, trained and representative of the diverse perspective of all breast cancer. That is why NBCC spends significant resources on educating and empowering advocates and helping them find their place at meaningful tables.

NBCC's trained research advocates are respected and recognized as the best educated and most effective advocates in the research and policy arenas. They receive their most intensive science training through **Project LEAD**[®], a key component of NBCC's Center for Advocacy Training.

LEADERS FOR PROJECT LEAD[®]

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.

In 2017, a diverse class of 41 advocates gathered for a week of intense, dedicated study. The class included participants from 14 different states, Puerto Rico and Spain.

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

After advocates have graduated from **Project LEAD**[®] courses, they continue their science education through the **Project LEAD**[®] Continuing Education Program.



Continuing Education for Project LEAD[®] Graduates

Through LEADgrads Online, an online community for **Project LEAD[®]** graduates and advocates analyze and discuss the latest in breast cancer research, advances and controversies and share advocacy opportunities in a web-based format. **LEADcasts** provides 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. In February, Dr. David Walt of the Wyss Institute at Harvard University and Dr. Rachel Buchsbaum of Tufts Medical Center presented ***The Promise of a Blood Test for Early Stage Breast Cancer***. In October, **Dr. Susan Love** of the Dr. Susan Love Research Foundation led the **LEADcast** titled ***The Normal Breast and Its Development*** and in November, Dr. Cyrus Ghajar of the Fred Hutchinson Cancer Research Center presented, ***The Immune System and Tumor Dormancy: Can we prevent lethal disease?***

In December, 85 **Project LEAD[®]** graduates gathered ahead of the San Antonio Breast Cancer Symposium for NBCC's annual **Project LEAD[®]** Advanced Topics Session. These advocates heard presentations from leading scientists about ongoing research into breast cancer metastasis. Dr. Alana Welm of the Huntsman Cancer Institute presented on the **Models of Breast Cancer Metastasis**, and Dr. Ghajar discussed **Dissemination, Early Seeding and Metastasis**. Advanced **Project LEAD[®]** advocates Nancy Ryan and Tracy Leduc provided their insights from a patient advocate perspective and shared information on the dynamic breast cancer vaccine landscape.

In addition, NBCC held Advanced Topics classes exclusively for **Project LEAD[®]** graduates at the Advocate Leadership Summit.

Online Center for Advocacy Training

The Online Center provides advocates from around the world an opportunity to hear some of the best thinkers in the world of breast cancer who have presented at NBCC's **Project LEAD[®]** courses, Advanced Topics sessions, Advocate Summits, **LEADcasts**, and more. In 2017, NBCC continued to develop our Online Center so that beginners and advanced learners alike can watch sought-after speakers and provocative thinkers discuss fascinating and controversial topics.



Advanced LEAD[®]

NBCC continued to test a new pilot training curriculum, Advanced **Project LEAD[®]**. This advanced program further trains advocates who have a deep interest in and propensity for taking leadership roles in breast cancer research advocacy as NBCC representatives. Building on the success of the 2016 program, advocates developed a three-part research proposal around understanding whether and how the immune system and disseminated tumor cells interact and whether the tumor microenvironment affects their interaction with immune system cells. Advocates were asked to propose a basic-to-preclinical-to-clinical study that was evaluated by faculty.

Team Leader Training

NBCC policy advocate leaders participated in Team Leader Training in March 2017 where 25 selected breast cancer advocates from around the country came to Washington 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.

ADVOCATE LEADERSHIP SUMMIT

An energized, committed and passionate group of NBCC leaders came together for our 2017 **Advocate Leadership Summit** in Arlington, VA. for networking, training and education in research and policy.

This year's preconference program began with a **Project LEAD**® workshop "Investigating the Etiology of Breast Cancer Metastasis Through Genetic and Genomic Screens." The Summit featured fascinating plenary sessions on immunology and primary prevention of breast cancer, as well as sessions about understanding and stopping metastasis. Attendees had the opportunity to hear about our new project DNA.Land, and the Metastatic Breast Cancer Project, explaining how your genome can help find answers to end breast cancer.

A luncheon arm chair discussion on ductal carcinoma in situ (DCIS), and an in depth discussion on various approaches to healthcare reform rounded out the plenary sessions. There were eight workshops that included an overview of research into brain metastasis, an overview of the Department of Defense BCRP, a tutorial on scientific peer review, social media, and the advocate's role in research. The summit focused on leadership development and equipped attendees with the support and information they need to advance the work of **Breast Cancer Deadline 2020**®.

Sessions at the 2017 Summit included:

- 📖 There is More Than One Path Forward: Different Approaches to Therapy
- 📖 Your Genome: How Can It Help Find the Answers We Need to End Breast Cancer?
- 📖 Approaches to Health Care Reform: How to Make Sense of It All
- 📖 Research Advocacy: How to Ask the Critical Questions
- 📖 How Can We Stop Women and Men from Getting Breast Cancer in the First Place?



ACCELERATING INNOVATION

in Research

The Artemis Project®

The research component of **Breast Cancer Deadline 2020®** includes 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

After several years of collaboration and research, and with work progressing rapidly on a pre-IND (investigational new drug) package, in 2017 we formally began interacting with the FDA to work toward approval of the Artemis preventive vaccine. At the March Artemis meeting, an international team of scientists with wide ranging expertise, together with advocates, produced a number of recommendations for the pre-clinical work leading to a clinical trial.

PREVENTION OF METASTASIS

Artemis participants produced a number of recommendations during 2017 for our work to prevent metastatic disease. Plans that outlined pre-clinical and clinical work towards immunologic and other approaches were developed, focusing on how tumor dormancy can be leveraged to prevent metastatic disease. As follow-up to the annual March meeting, a small group of Artemis participants met in New York, in April. The meeting included an update on Ductal Carcinoma in Situ research that was facilitated through an Artemis seed grant as well as further discussion about the metastasis project.

A summary report from the 2017 **Artemis Project®** meetings is available online:
Breastcancerdeadline2020.org/artemisproject.

DNA.Land

In May 2017, the project DNA.Land officially launched. 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. The goal is to develop a database resource to help determine why some individuals with breast cancer recur. By the end of 2017, approximately 9,000 people had completed the clinical questionnaire specific to breast cancer as part of the project.

ADVOCATE INFLUENCE

In 2017, 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 Board of Directors of the Institute for Clinical and Economic Review. For a full list, please visit www.deadline2020.org/NationalCommittees.



PUBLIC POLICY

NBCC's Board of Directors establish NBCC's legislative and public policy priorities. Each year, issues are brought to NBCC's attention by advocates, policy makers, researchers and the general public. NBCC staff researches each issue, and prepares background information for the Board. The Board discusses all suggested priorities at the January board meeting and votes on issues NBCC will adopt.

Visit breastcancerdeadline2020.org for NBCC's comprehensive list of 2017 priorities.

Two of the legislative and public policy priorities are highlighted below.

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.

NBCC'S ROLE IN PROTECTING THE AFFORDABLE CARE ACT

Ensuring access to affordable and quality healthcare for women and men with and at risk of breast cancer, has long been one of NBCC's top priorities. NBCC advocates worked in collaboration with many other groups, to fight attempts to repeal the Affordable Care Act in 2017. NBCC's network stepped up and its voice was essential in the strong advocacy that ultimately defeated Congressional action to undermine the ACA.

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 in May, where over 240 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 48 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 presence on Facebook, Twitter and YouTube, enabling us to communicate effectively with our audience. These sites provide new and returning audiences with information about NBCC programs and events, as well as important facts about breast cancer. Social media campaigns during the past year were built around major events such as breast cancer awareness month, Giving Tuesday and select holidays highlighting, through photos and videos, NBCC's mission to end breast cancer.

Fran Visco continues to comment on breast cancer news and health care policy with statements appearing in news outlets such as the **New York Times**, **CNN**, **NPR**, the **Chicago Tribune**, and **USA Today**. In January, she spoke with both **Kaiser Health News** and **NPR** about a Danish mammography study and also wrote a letter to the editor of The New York Times in response to an article entitled "Taxpayers Finance Cancer Drug, but the Profits Will Be Private." The article highlighted problems in the system of research that results in drugs that do not save lives and that few can afford.

In March, **The Cancer Letter** published its conversation with Fran, where she discussed how scientists and patient advocates should be partners on every level, not just when the National Institute of Health (NIH) budget is threatened.

In June, Yale hosted an international meeting that Fran participated in titled "*Ensuring Safety, Efficacy, and Access to Medical Products in the Age of Global Deregulation.*" She contributed to the university's blog, *CRITICAL Thinking*, with a piece arguing that an informed patient advocacy perspective is vital to ensuring the integrity and transparency of the research process. In December, she gave a Google Talk on "*Innovation in Breast Cancer Prevention and Treatment.*"

KEY EVENTS

Les Girls

NBCC's 17th 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. In 2017, the event was hosted by Lauren Shuler Donner and NBCC honored Dennis J. Slamon, M.D., PhD. with the 2017 Les Girls Leadership Award, for his dedication to saving lives and his commitment to women's health. Our spectacular celebrity entertainers such as Sharon Lawrence, Jean Smart, Ann Cusack and Steven Weber performed.

Gala

NBCC's 22nd New York Gala, included co-chairs Fabian Garcia, President and CEO of Revlon; Mark J. Alles, CEO of Celgene; and Sharon Nelles, Partner, Sullivan & Cromwell, and our dinner committee chairs: Dorian Goldman and Marvin Israelow, Liane and Luca Lindner, Violaine and John Bernbach and Carol and Terry Wall. The Gala was a great success and we were very proud to honor Stephanie Disegni, President/CEO, Longchamp USA and Hinrich J. Woebcken, President/CEO, Volkswagen Group of America for their work in support of our cause. As always, the highlight of the Gala was hearing from our Grassroots Advocacy Award honorees. Our 2017 recipients Medha Deoras-Sutliff and Alysia Pringle were presented with awards by our gracious special guest Amanda Stephens from Orange is the New Black. Guests enjoyed an incredible performance by Laura Bell Bundy, recording artist and actress.

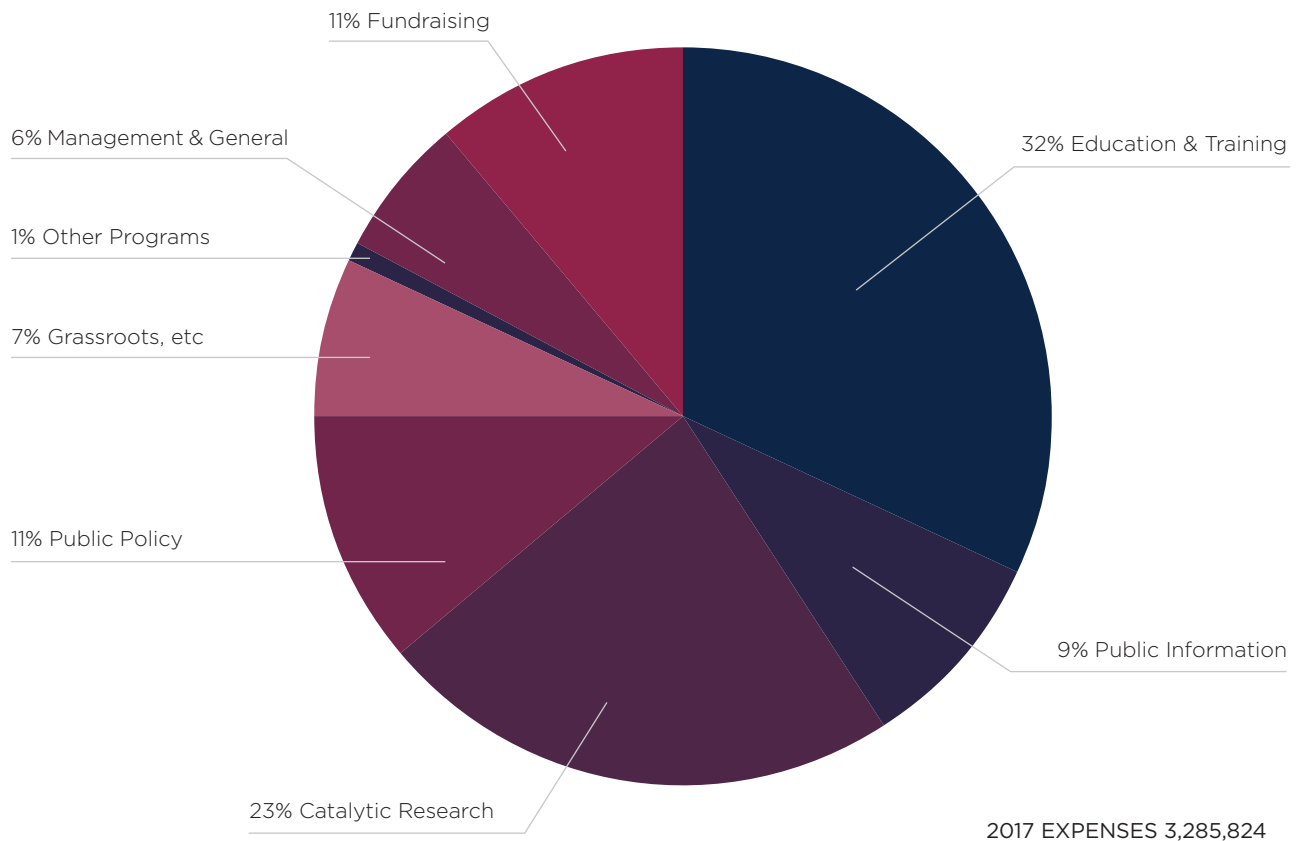
NYC Women with Balls[®]

The inaugural NYC Women with Balls[®] bowling fundraiser was held at the Bowlmor Lanes in Times Square in May. 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.

Double Standards

On November 12th, Tony Award nominee Laura Bell Bundy gathered fellow performers for Double Standards, a benefit concert in support of women's issues. The benefit was sponsored by NBCC long-time supporter iSCLINICAL. NBCC was one of the beneficiaries of the star-studded event that included Laura Bell, Jessie Mueller, Denee Benton, Sara Bareilles, Rosie O'Donnell and other performers that set the stage for an incredible evening of fun and philanthropy.

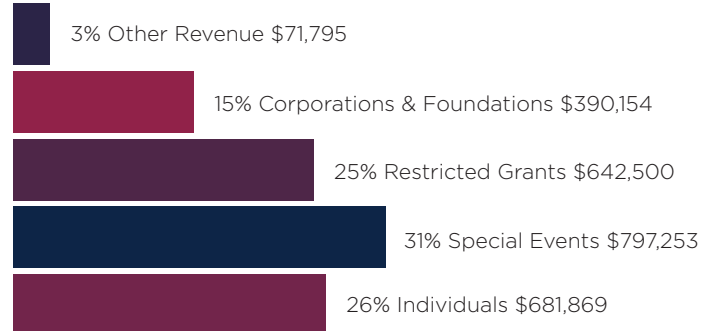
YOUR DOLLARS AT WORK



ASSETS

Cash & Cash Equivalents	\$ 572,550
Accounts Receivables	\$ 1,511,904
Prepaid Expenses	\$ 70,381
Net Property & Equipment	\$ 245,145
Deposits	\$ 57,134
TOTAL ASSETS	\$ 2,475,897
LIABILITIES	\$ 503,209
TOTAL NET ASSETS	\$ 1,972,688
TOTAL LIABILITIES & ASSETS	\$ 2,475,897

2017 PUBLIC SUPPORT & OTHER REVENUE 2,583,571



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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.