



2016

NATIONAL BREAST CANCER COALITION

Annual Report



A Message From The President

During 2016, NBCC made great progress towards Breast Cancer Deadline 2020® and our mission to end breast cancer. The annual meeting of the Artemis Project® included more than 40 advocates and scientists with expertise ranging from immunology, biophysics, and genetics, to molecular biology, and clinical oncology. They continued to develop plans of action to prevent breast cancer and stop women and men from dying of it. NBCC partnered with the New York Genome Center on a new project, DNA.Land, that received a seed grant from the Artemis Project to develop a large scale resource for studying breast cancer genomics. We continued to train advocates to be partners in science through our Project LEAD® Institute, our most intensive science course, with a curriculum including cancer biology, genetics, DNA, RNA, proteins, epidemiology and much more.

NBCC once again saved funding for the Department of Defense Breast Cancer Research Program which was threatened in 2016. Senator John McCain included language in the National Defense Authorization Act that would have done away with the program. NBCC acted immediately and with urgency and organized 71 groups to co-sign a letter to both the Chairman and Ranking Member of the Senate Committee on Armed Services opposing the problematic language. We also mobilized our advocacy network to send Congress the message to save the program. As you read our 2016 annual report, you will learn more about NBCC's education, science and public policy work throughout the year.

The pivotal event of 2016 was undoubtedly the U.S. presidential election. The result has put a great deal of pressure on maintaining access to affordable, quality healthcare and funding for meaningful science. NBCC will continue to work and fight on the front lines to defend our right to healthcare, and to ensure that scientific research moves forward, not backwards - with your continued support and action.



FRAN VISCO
PRESIDENT, NATIONAL BREAST CANCER COALITION

Training Advocate Leaders In Science And Policy

We will only end breast cancer if trained and educated advocates lead the way. NBCC's programs are designed to support a network of advocates who can change systems of research and advance meaningful public policy.

PROJECT LEAD INSTITUTE GRADUATES A NEW CLASS OF RESEARCH ADVOCATES

NBCC's trained science research advocates are respected as the best educated and most effective in the scientific and advocacy communities. They receive their most intensive education at the Project LEAD Institute, part of NBCC's Center for Advocacy Training. Over 40 graduates completed the 2016 Institute in July and continue to be supported by NBCC mentors. Nearly 2,500 advocates have been trained through Project LEAD since its inception in 1995. Project LEAD provides breast cancer advocates with the information and tools they need to collaborate with scientists and understand and translate complex scientific and medical information. Project LEAD also helps breast cancer advocates understand the nuances of research methodology and the unique role advocates play in influencing the research agenda.

Graduates of Project LEAD are rigorously trained and continue to play critical roles in areas such as the Department of Defense Breast Cancer Research Program, NBCC's Artemis Project, key clinical trials, research institutions around the country and worldwide, and have a credible voice anywhere decisions about breast cancer are being made. They are better able to analyze and interpret breast cancer information in their communities.

In 2016 we also pilot tested a new training curriculum, Advanced Project LEAD. This program is meant to further train advocates who have a deep interest in, and propensity for, taking leadership roles in breast cancer research advocacy as NBCC representatives.

Ongoing education and training for Project LEAD graduates are offered throughout the year and included a series of workshops including "High-Throughput Analysis of Genomic, Epigenetic and Proteomic Alterations in Cancer Cells," "The Emergence of Immunotherapy and the Potential in Breast Cancer," "Neoadjuvant Endocrine Therapy for Prediction and Prognosis in ER+ Breast Cancer," and "Analysis of Biomarkers and Genomic Tests."



THE 2016 ADVOCATE LEADERSHIP SUMMIT

An intensive three days of plenary sessions and workshops, the Summit was capped by a full day of advocate meetings on Capitol Hill to further NBCC's legislative agenda.

Commemorating NBCC's 25th year, speakers at a special luncheon looked back to the founding of the organization. Twenty-five years of advocacy was recognized and attendees heard about key moments in the organization's journey from advocates who helped make those moments happen.



HIGHLIGHTS OF THE 2016 SUMMIT INCLUDED:

- After 25 Years, What Do We Really Know About Preventing Metastasis?
- Complexities of Metastatic Breast Cancer Research
- After 25 Years, What Do We Really Know About Preventing Breast Cancer?
- Breast Cancer is Political: Mobilizing in the 2016 Political Environment
- Health Disparities in Breast Cancer
- Vaccine Development: A Primer
- Is This Truly an Era of Personalized Medicine?
- The Immune System and Breast Cancer: Where are We?
- Ramp Up Your Critical Appraisal Skills and Get Ready for Scientific Peer Review
- Strategic Advocacy

Videos of the sessions are available:
www.breastcancerdeadline2020.org/Summit2016

Accelerating Innovation In Research

NATIONAL BREAST CANCER COALITION

ARTEMIS PROJECT

THE ARTEMIS PROJECT

The Artemis Project is an advocate led, mission driven research program consisting of strategic summits, catalytic workshops, research action plans and collaborative efforts of various stakeholders. Artemis Project participants design and implement research plans and interact through an infrastructure maintained by NBCC that allows collaborations to thrive and progress rapidly. The Artemis Project focuses on two areas:

- **Primary Prevention:** How do we stop people from getting breast cancer?
- **Prevention of Metastasis:** How do we stop people from dying of breast cancer?

The 2016 annual meeting was held in March and included more than 40 advocates and scientists with expertise ranging from immunology, biophysics, and genetics, to molecular biology, and clinical oncology.

PRIMARY PREVENTION—PREVENTIVE VACCINE PROJECT

Building on the 2015 meeting where protein targets were selected to be incorporated into the vaccine and the work done over the prior twelve months, participants discussed a review of the vaccine landscape and advances in science that may affect prevention. At the meeting, a research and regulatory path for the preventive vaccine were presented and discussed. The ongoing work looking at a molecular framework of early breast cancer was analyzed by the participants.

PREVENTION OF METASTASIS PROJECT

Artemis participants identified and discussed topics and developed plans of action to prevent metastasis including clinical trials, an approach to metastatic relapse and triggers, the relevance of disseminated tumor cells and how to intercede, in addition to approaches to circulating tumor DNA, the lymph node niche, and CMV virus.



DNA.Land, a project of the New York Genome Center, received a seed grant from the Artemis Project to develop a large scale resource for studying breast cancer genomics. This project involves the development of a database of at least 25,000 individuals by crowd sourcing the collection of genotype/phenotype data by leveraging DNA information from direct to consumer (DTC) genomics companies such as 23andMe, AncestryDNA, FamilyTreeDNA, or MyHeritage. Participants upload their genomic information to the database and answer a series of clinical questions. The participants are also able to upload their family tree and share information about breast cancer of other family members. The questionnaire links clinical information with genomic data allowing researchers to ask questions about breast cancer recurrence and progression in new ways.

The 2016 and previous Artemis Project reports are available online: <http://www.breastcancerdeadline2020.org/about-the-deadline/artemis-project.html>



NBCC ADVOCATE INFLUENCE

NBCC advocates [Board Members, Project LEAD graduates and members] continue to be active on national and international committees dedicated to furthering breast cancer research and care. In 2016, some examples included 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, the Board of Trustees of TRIO, a global clinical trials consortium, the Board of Directors of the Institute for Clinical and Economic Review and steering committees, and data safety monitoring committees of clinical trials for new therapies. In addition, NBCC participated in several Moonshot projects and summits, including a roundtable of patient groups that met with Vice President Biden and Dr. Jill Biden.

Public Policy

DOD BREAST CANCER RESEARCH PROGRAM (DOD BCRP)

NBCC's 2016 advocacy successfully brought about another \$120 million for worldwide breast cancer research, through the DOD program, bringing that total to over \$3.3 billion. That success was hard fought. In May 2016, Senator John McCain (R-AZ) included language in the National Defense Authorization Act (NDAA) that would have undermined and restricted the research efforts conducted by the Congressionally Directed Medical Research Programs, including the DOD BCRP. In response, NBCC arranged for over 70 organizations to sign on to a letter supporting the DOD BCRP, which was sent to the Senate Committee on Armed Services. Our network made certain all Senators knew of our opposition. A champion of the CDMRP's, and the 2015 New York Gala honoree, Senator Dick Durbin (D-IL) introduced an amendment to help repeal the harmful provisions, and with the help of NBCC advocates, the amendment passed. NBCC Vice President Wanda Jones spoke at the press conference on Capitol Hill raising awareness about the need to protect the program.

ACCELERATING THE END OF BREAST CANCER ACT

The Accelerating the End of Breast Cancer Act (AEBCA) was written to complement and enhance the strategic work being done by NBCC to help know how to end breast cancer once and for all. Advocates came to Washington from across the country to urge their Representatives and Senators to take action and pass the AEBCA. The 114th Congress ended without voting on the bill, although NBCC advocates had garnered widespread bipartisan support with a total of 274 Representatives and 54 Senators as cosponsors.

BREAST CANCER CAUCUS

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 inform the public where the candidates stand on NBCC's agenda. For the 2016 campaign, NBCC asked every candidate to endorse Breast Cancer Deadline 2020 and explain what actions they would take on related public policy priorities. NBCC advocates collected endorsements from Democratic candidate Hillary Clinton and Republican candidate John Kasich. Before suspending their campaigns, Republican candidates Jeb Bush, Chris Christie, Lindsay Graham and Bobby Jindal, as well as Democratic candidate Martin O'Malley, also endorsed the deadline.



HONORING OUR CONGRESSIONAL LEADERS

NBCC honored U.S. Congressman John Lewis (D-GA-5) with the first-ever Deadline Champion Award for his leadership in NBCC's mission to end breast cancer. Congressman Lewis was a cosponsor of *Accelerating the End of Breast Cancer Act*, has endorsed Deadline 2020, and supports NBCC efforts to educate and engage new grassroots advocates. He was an integral part of the Community Forum in Atlanta, which brought together grassroots organizations, key stakeholders, and elected officials in order to educate and activate participation in this public health crisis.

LOBBY DAYS

NBCC hosted the annual Advocate Leadership Lobby Day, when advocates from across the country visited Congressional offices and used social media to advance Breast Cancer Deadline 2020. Advocates also urged their Members of Congress to continue to support the DOD BCRP which funds innovative, high-risk, high-return research.

Additionally, a special lobby day was held in September which built on a summer of intense grassroots activism directed at House leadership to urge movement of H.R. 1197 (the Accelerating the End of Breast Cancer Act) to the House floor for a vote. Advocates converged on Washington from across the country to meet with and impress upon Members of Congress the importance of the legislation and urged them to take action to enact the Bill.

Grassroots mobilization efforts continue to advance our work to change the conversation in communities across the nation. Advocates are making creative outreach efforts to gain support for Breast Cancer Deadline 2020 from organizations and public officials.

Outreach And Media

In the Spring/Summer 2016 issue of *New Atlantis*, NBCC was featured in an article entitled “Saving Science” by Daniel Sarewitz. The article highlights NBCC’s leadership in advancing innovative science and challenging the status quo in research, as well as its role in major research programs. NBCC President, Fran Visco continues to comment on the breast cancer news of the day with statements that appeared in *USA Today*, *CNN*, *Yahoo*, the *Boston Globe*, *Voice of America* and *NPR*. In addition, Visco, blogs at *Huffington Post* to help promote the Breast Cancer Deadline 2020 campaign and participates in media interviews. Some of the blog posts in 2016 included *Cutting Through the Breast Cancer Clutter* and *Every Day is Metastatic Breast Cancer Awareness Day for NBCC*.

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 encourage women to learn the truth about breast cancer in order to make informed decisions regarding their health care.

NBCC continued to maintain an active presence on Facebook, Twitter and YouTube, enabling us to communicate effectively with these audiences. These sites reach 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 built around major events such as breast cancer awareness month (Pink is Not Enough), Giving Tuesday and select holidays used photos and videos to highlight NBCC’s message of knowing how to end breast cancer and save lives by 2020.




Saving Science

Science isn't self-correcting, it's self-destructing. To save the enterprise, scientists must come out of the lab and into the real world.

Daniel Sarewitz


Science, pride of modernity, our one source of objective knowledge, is in deep trouble. Stoked by fifty years of growing public investments, scientists are more productive than ever, pouring out millions of articles in thousands of journals covering an ever-expanding array of fields and phenomena. But much of this supposed knowledge is turning out to be contestable, unreliable, unusable, or flat-out wrong. From metastatic cancer to climate change to growth economics to dietary standards, science that is supposed to yield clarity and solutions is in many instances leading instead to contradiction, controversy, and confusion. Along the way it is also undermining the four-hundred-year-old idea that wise human action can be built on a foundation of independently verifiable truths. Science is trapped in a self-destructive vortex; to escape, it will have to abdicate its protected political status and embrace both its limits and its accountability to the rest of society.

The story of how things got to this state is difficult to unravel, in no small part because the scientific enterprise is so well-defended by walls of hype, myth, and denial. But much of the problem can be traced back to a bald-faced but beautiful lie upon which rests the political and cultural power of science. This lie received its most compelling articulation just as America was about to embark on an extended period of extraordinary scientific, technological, and economic growth. It goes like this:

US
EDITOR

THE BLOG 02/17/2016 02:55 pm ET | Updated Feb 17, 2017

Cutting Through the Breast Cancer Clutter

 By Fran Visco

It is a new year, and unfortunately, we can expect 2016 to bring more sensational breast cancer headlines. Think of some headlines we saw in 2015: Everyone over age 30 should be tested for the BRCA gene mutation. Olive oil may help prevent breast cancer. A virus found in cattle is linked to increased breast cancer risk. How do you know what is true, what is hype and what is misinformation?

It can be overwhelming to someone who has been diagnosed with breast cancer or for someone helping a loved one navigate the maze of information surrounding this disease. Conflicting messages, oversimplification of complex studies and just plain misinformation about causes, treatment, scientific breakthroughs and “miracle” medicines can be found far and wide.

The National Breast Cancer Coalition (NBCC) wants to help you cut through the breast cancer clutter by answering the crucial question, “How do I decide what to believe?”

What should I look for in a news story about a research study?

Your introduction to a research study will likely come from a headline, a newspaper article or a story you see on the evening news. Or you will find various blogs and other sources of information on the web. Many of these are summaries of the latest in health care research and can oftentimes sound dire or too good to be true. The truth usually lies somewhere in between.

HealthNewsReview, an online reviewer of health care intervention stories, has [helpful criteria](#) they use to evaluate the news. You can take some of their criteria into consideration: Does the article exaggerate the condition? Over-sell symptoms as diseases themselves? Does the article include the cost of a new intervention? Cite the harms of the intervention? Include perspectives from the other side?

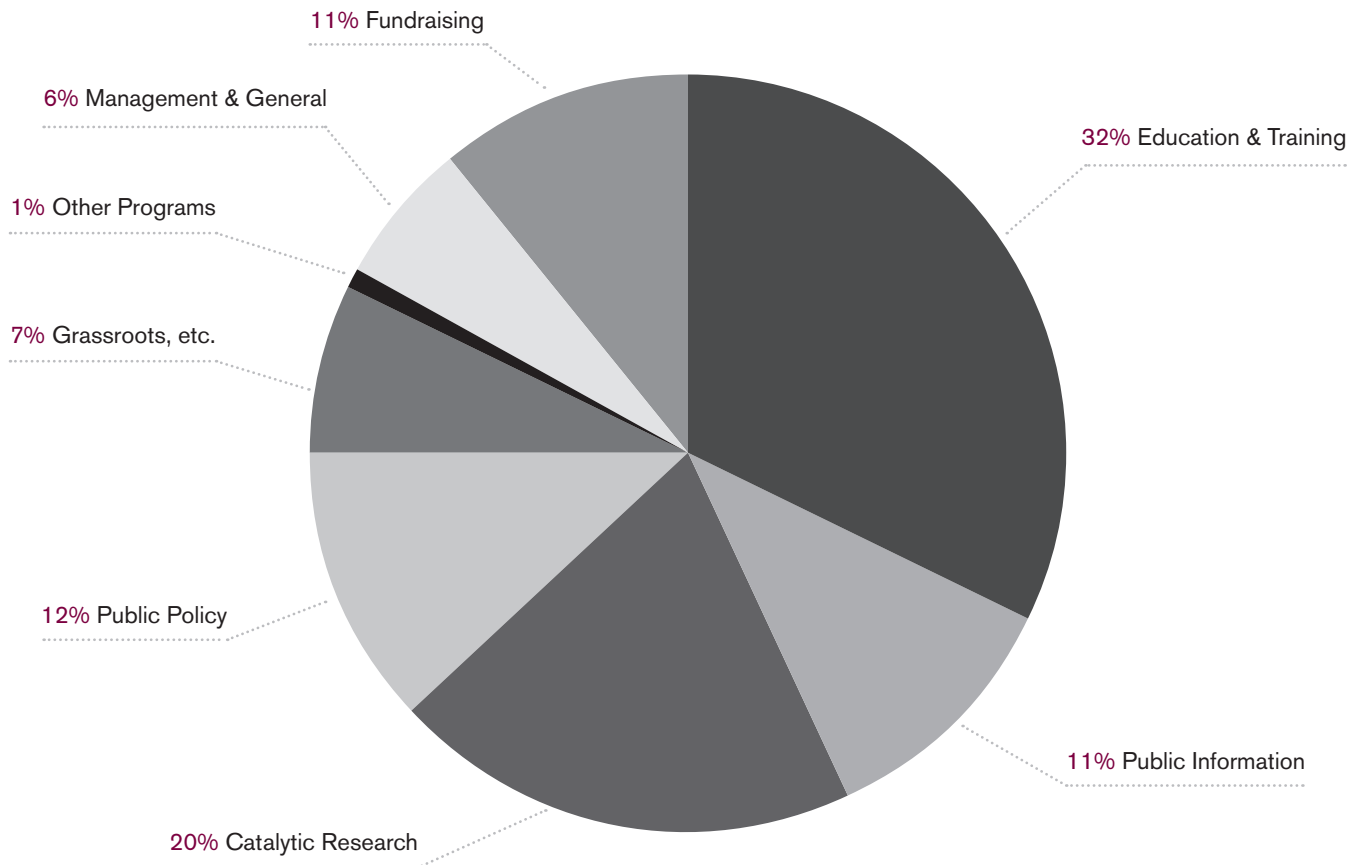
Key Events

NBCC's 16th annual Les Girls Cabaret, was held in October in Los Angeles, and brought together attendees to recognize Courtney Hollander for her dedication to advancing breast cancer awareness by sharing her story. Hosted by Ari Graynor, spectacular entertainers, such as Richard Kind, Lea Thompson and Rachel Bloom joined forces to make the evening memorable. A fun-filled evening to support NBCC's important work!

NBCC's 21st Annual New York Gala was a sold out event. Alongside special guest, Phylicia Rashad, Gala Chairs Fabian Garcia, President and CEO of Revlon, Mark Alles, CEO of Celgene and Stephanie Disegni, President and CEO, Longchamp USA, hosted a successful evening for NBCC's work. NBCC honored two dedicated NBCC advocates, Shirley Brown and Marlene McCarthy for their many years of advocacy on our behalf. NBCC's 2016 Leadership Award was presented to Judges and Lawyers Breast Cancer Alert, an organization that is a major supporter of Project LEAD, in addition to community programs that offer legal and social support to families in crisis.



Your Dollars At Work

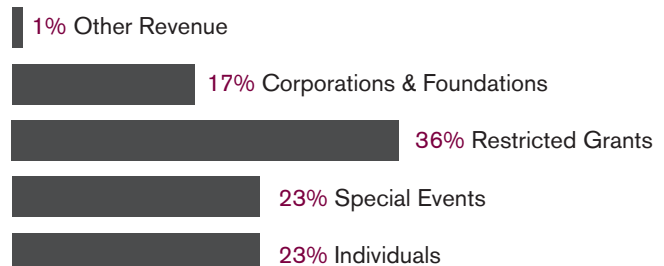


2016 EXPENSES \$3,236,758

ASSETS

Cash & Cash Equivalents	\$425,800
Accounts Receivables	\$3,813,797
Prepaid Expenses	\$62,855
Net Property & Equipment	\$371,925
Deposits	\$38,089
TOTAL ASSETS	\$4,712,466
LIABILITIES	\$1,025,456
TOTAL NET ASSETS	\$3,687,010
TOTAL LIABILITIES & ASSETS	\$4,712,466

2016 PUBLIC SUPPORT & OTHER REVENUE \$2,847,957



2016 President's Council

The President's Council is a national network of like-minded women and men who provide the leadership and financial support to the National Breast Cancer Coalition Fund in our mission to end breast cancer. Our President's Council members are key ambassadors, reaching into their own communities and networks on our behalf.

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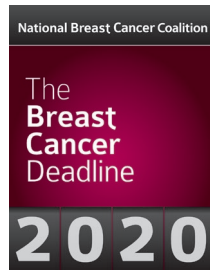
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The **National Breast Cancer Coalition Fund** is a 501(c)(3) entity that designs and runs programs to educate, train, and inform advocates, policy makers, scientists, providers, and the public about science, health care and advocacy. The Fund collaborates 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.