2019 Accomplishments and Actions

RESEARCH

NBCC's Artemis Project®, an advocate-led, innovative, mission-driven approach of strategic summits, catalytic workshops, research action plans and collaborative efforts of various stakeholders, focuses on 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 to report on accomplishments and develop plans for the next 12-18 months. Throughout the year, participants engage in webinars and conference calls to refine plans and provide additional input.

Artemis Project for Prevention of Metastasis
A subgroup began to look specifically at technology needed to help answer the 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.

Artemis Project® for a Preventive 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 progress the Phase I trial. In addition, the 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+ 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 project DNA.Land officially launched. DNA.Land asked 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. 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.

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 HealthNewsReview.

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 and/or their staff members to discuss and forward NBCC’s legislative and public policy agenda. NBCC’s trained Team Leaders 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”, an update on the progress of the Artemis Project and health care policy in the present 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 have 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**

In 2019, NBCC hosted another successful Project LEAD Institute in La Jolla, California this past July. With a diverse class of 58 advocates, 2019 had one of the largest classes ever — and 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 (NBCC) 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 vote on the top legislative priorities. In 2019, NBCC made significant progress on these 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 (an increase from $130 million for FY 2019) for FY 2020.

**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. As of January 31, 2020, NBCC has brought about 134 cosponsors in the House and 16 in the Senate.

**Annual Membership Lobby Day**

Our annual membership lobby day in April, saw NBCC advocates hold 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.

As 2019 drew to a close, we were proud of the work we had accomplished, and look forward to another year of bold advocacy in action in 2020.