



Deadline 2020[®] White Paper

Summary

In 2010, the National Breast Cancer Coalition (NBCC) set a deadline to know how to end breast cancer by January 2020. We knew achieving this audacious goal would require fundamental changes in research priorities, financial incentives, funding mechanisms and advocacy efforts. We knew it would require harnessing the energy and resources of researchers, public officials, business leaders, the philanthropic and funding community, breast cancer advocates and the general public. We knew we could fail. We did it anyway.

We are gratified to report that we are remarkably close to reaching our goal. Spurred by the renewed urgency of the deadline, we launched our boldest initiatives yet with remarkable results. An NBCC-led collaboration has developed a preventive vaccine, designed the protocol and initiated the U.S. Food and Drug Administration (FDA) process in order to begin testing the vaccine in people. Clinical trials are scheduled to begin in late 2020.

Is this the beginning of the end of breast cancer? Until the research process is complete, no one can make such a claim. And until breast cancer is eliminated, or no longer harmful, our progress is inadequate. But a decade of commitment to the singular goal of ending breast cancer has made many impossible things become possible.

When we set the deadline, we knew we needed a fundamental change in the national conversation on breast cancer. This has happened. There has been a cultural shift away from pink ribbons and simplistic messaging like “mammograms save lives,” and toward a stronger appreciation of evidence-based medical research and health care. More breast cancer research is focused on what matters most: stopping people from getting breast cancer in the first place (primary prevention) and stopping them from dying of it. The idea that scientific discovery is impeded by worldly burdens like deadlines is fading, and “research in a silo” is now increasingly supplemented with mission-driven collaborations. The notion that science needs to be protected from the dangerous influences of advocates has—we hope—been discarded. Advocate leadership, accountability with deadlines and extensive collaboration are now embraced not only by advocates, but also by business leaders, elected officials and much of the scientific community.

We also knew that to end breast cancer, we would need bold national and international leadership, an unfailing urgency and an unwavering focus. That did not come about. We did not expect to experience the worst global recession since the Great Depression or see a fundamental shift in values from those in federal office. Still, deadlines inspire, and deadlines focus. There were those who were content to “keep their heads down,” inching along with the status quo and satisfied with incremental change. We created a different, bolder space.

This report tells the story of Deadline 2020—how the science, business and politics of breast cancer brought us to set a deadline, what we learned from taking on such a bold goal, our progress toward ending breast cancer and our next steps.

In that space, meaningful cultural and scientific progress has been made, bringing us closer to ending breast cancer.

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This tumultuous decade is ending with the world’s worst pandemic in more than 100 years, overshadowing every aspect of our lives and shattering everything we once considered to be “normal.” It is a scary time with uncertainty everywhere.

Here is one thing that is certain. NBCC will remain laser focused on our mission to end breast cancer. We will be relentless as we advocate for meaningful progress, calling for bold new ideas and calling out corporate greed, political platitudes, and academic conservatism and stagnation. We refuse to accept the debilitating and life-threatening disease of breast cancer as inevitable.

After a decade of deadline-driven advocacy, we are more confident than ever that this can be done. Dying of breast cancer can become a relic of the past—a story that our children will never have to tell. Until then, NBCC will carry on. We hope you will join us.

1. How We Got Here

Breast cancer is a complex disease that has killed millions. It also created a booming business and a massive social movement. This tangled web of private pain, public attention, corporate interests and conflicting agendas created a unique phenomenon that is the story of breast cancer.

A. The Disease of Breast Cancer

Breast cancer has been a conundrum for at least 5,000 years, which is when cases of breast cancer were first recorded in medical writings. For most of that time, the diagnosis was a death sentence; local surgery was sometimes performed, but it was more heroic than effective given the lack of anesthesia and aseptic techniques available.¹ During the 18th century, physicians began to notice that axillary nodal involvement appeared to be a factor in breast cancer disease progression. This spurred the idea that, at its earliest stage, breast cancer was a local disease that could be effectively treated by surgery, leading to the “slash (surgery), burn (radiation), and poison (cytotoxic drugs)” method that continues today.

Slash, Burn, and Poison

In the 19th century, anesthesia and antiseptics dramatically improved patient care.² By then, most doctors believed that cancer grew in an orderly manner, starting very small and gradually growing larger, with a constant and linear path of dissemination from breast to axillary nodes and only then to distant locations in the body.³ Based on this view, William Halsted developed the radical mastectomy, which involved removing the entire breast, along with the pectoral muscles, lymphatic vessels and the axillary lymph nodes.⁴ Despite the fact that mortality statistics remained unchanged, radical mastectomy continued for three-quarters of a century.⁵

¹ Sakorafas GH, Safioleas M. Breast Cancer Surgery: An Historical Narrative. Part I. From Prehistoric Times to Renaissance. *Eur J Cancer Care*. 2009 Nov;18(6): 530-44. Hippocrates first introduced the idea that illness has natural—not supernatural—causes. That led to the humoral theory—the belief that four humoral liquids in the body cause all disease. This remained the leading theory of disease until the 18th century.

Lagay F. The Legacy of Humoral Medicine. *Virtual Mentor*. 2002 Jul 1;4(7): virtualmentor.2002.4.7.mhst1-0207.

² Sakorafas GH, Safioleas M. Breast Cancer Surgery: An Historical Narrative. Part II. 18th and 19th Centuries. *Euro J Cancer Care*. 2010 Jan 1;19(1):6-29. The introduction of microscopic examination also led to a better understanding of the biology of cancer.

³ The stages of breast cancer (size of tumor, whether it has spread to the lymph nodes and whether there is evidence of metastasis) reflect this orderly and linear understanding of cancer. The American Joint Committee on Cancer published the first tumor, node, metastasis (TNM) system for staging cancer in 1959. There are now eight editions, the most recent one in 2017.

Koh J, Kim MJ. Introduction of a New Staging System of Breast Cancer for Radiologists: An Emphasis on the Prognostic Stage. *Korean J Radiol*. 2019 Jan;20(1):69-82. Breast cancer staging has been revised over the years. Current factors in staging include tumor size, lymph node status, estrogen-receptor and progesterone-receptor levels in the tumor tissue, human epidermal growth factor receptor 2 (HER2/neu) status in the tumor, tumor grade, menopausal status and general health of the patient.

PDQ® Adult Treatment Editorial Board. PDQ Breast Cancer Treatment. Bethesda, MD: National Cancer Institute. Updated 04/19/2019.

⁴ While it is true that in the early 1900s the Halsted radical mastectomy was the only option in most parts of the U.S., Cleveland Clinic surgeon George W. Crile treated breast cancer with a cosmetically excellent, modified radical operation. He described Halsted as “an obsessional fuddy-duddy who takes all day to do an operation that should never be done at all ... radical mastectomy seems to have been designed to inflict the maximal possible deformity, disfiguration and disability.”

Sakorafas GH, Safioleas M. Breast Cancer Surgery: An Historical Narrative. Part III. From the Sunset of the 19th to the Dawn of the 21st Century. *Euro J Cancer Care*. 2010 Mar;19(2):145-166.

⁵ Lerner BH. 2003. *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America*. 1st ed. New York: Oxford University Press. Comparing various forms of super-radical, extended-radical and other modified surgical procedures was an early lesson that “more” is not necessarily better when it comes to health care interventions.

It wasn't until the 20th century that some physicians began to systematically follow—and document—their patients' health. Collecting and analyzing data created a new way to practice medicine, and physicians began to use statistical analysis to evaluate the effectiveness of their interventions. Although surgery continued to dominate, physicians introduced systemic therapies, including chemotherapy, hormonal therapy and radiation. There was a glimmer of good news in the mid-1980s: Research showed breast-conserving surgery followed by radiation was as effective as mastectomy, providing women with more options.⁶ There was no cure or prevention in sight, but these options at least lessened the horror of breast cancer for some women.

Hormone Therapy

The link between hormones and cancer has been known since the beginning of the 20th century, but it was a failed attempt to create an emergency form of contraception that led to the first, and one of the world's most prescribed, hormonal breast cancer drugs: tamoxifen.⁷ Initially approved by the FDA in 1977 for the treatment of metastatic breast cancer,⁸ tamoxifen, and now other hormone-based treatments, have been shown to be effective in the adjuvant setting for some types of early stage breast cancer.⁹

Targeted Therapy

Through determination and novel partnerships, researchers in the 1980s and 1990s developed what has been, until recently, one of the most unprecedented discoveries in oncology: trastuzumab (Herceptin[®])—a targeted, non-chemo based treatment for a specific breast cancer subtype.¹⁰ This, among earlier discoveries, made it clear that not all breast cancers are the same.¹¹ As a result, the medical oncology community began to embrace and market the concept of personalized, or individualized, medicine, but it was—and continues to be—aspirational: The majority of women with breast cancer—even those who receive targeted therapies—continue to receive the same slash, burn and poison treatment.

⁶Physicians developed a technique that allows them to examine tissue during surgery, which means, if needed, excision can be performed immediately. It also means that if tissue is not cancerous, the patient can avoid further invasive procedures. See Sakorafas GH, Safioleas M. Breast Cancer Surgery: An Historical Narrative. Part III supra 147-148.

⁷Quirke VM. Tamoxifen from Failed Contraceptive Pill to Best-Selling Breast Cancer Medicine: A Case-Study in Pharmaceutical Innovation. *Front Pharmacol.* 2017;8:620.

⁸Fisher B, Redmond C, Brown A, et al. Adjuvant Chemotherapy With and Without Tamoxifen in the Treatment of Primary Breast Cancer: 5-Year Results From the National Surgical Adjuvant Breast and Bowel Project Trial. *J Clin Oncol.* 1986 Apr;4(4):459-71.

⁹Controlled Trial of Tamoxifen as Adjuvant Agent in Management of Early Breast Cancer. Interim Analysis at Four Years by Nolvadex Adjuvant Trial Organisation. *Lancet.* 1983 Feb 5;1(8319):257-61. Because tamoxifen was effective for breast cancer that was hormone-receptor positive (HR+) but not for breast cancer that was hormone-receptor negative (HR-), this spurred additional research on the subtypes of breast cancer.

¹⁰Studying frozen breast cancer tumor samples that he collected for research and bringing his results into clinical trials, oncologist Dr. Dennis Slamon demonstrated that people whose breast cancer tested positive for overexpression of a protein called human epidermal growth factor receptor 2 (HER2) have a worse prognosis than those with HER2-negative tumors. Slamon DJ, Clark GM, Wong SG, et al. Human Breast Cancer: Correlation of Relapse and Survival With Amplification of the HER-2/neu Oncogene. *Science* 1987 Jan 9;235:177-82.

Bazell R. Herceptin: What it took to make it happen. *The Cancer Letter* 2019 Sept 20;45(35):5-9.

¹¹That a monoclonal antibody was effective in that population was met with much skepticism and opposition from the traditional research and medical community. Prat A, Pineda E, Adamo B, et al. Clinical Implications of the Intrinsic Molecular Subtypes of Breast Cancer. *Breast.* 2015 Nov; 24 Suppl 2:S26-35, as cited in Koh J, Kim MJ. Introduction of a New Staging System of Breast Cancer for Radiologists: An Emphasis on the Prognostic Stage. *Korean J Radiol.* 2019 Jan;20(1):69-82.

The Harm of Treatment

Meanwhile, it became clear that the treatments for breast cancer carry their own serious risk of harm. For instance, axillary lymph node dissection to remove lymph nodes in the breast and axillary region can result in a painful chronic condition called lymphedema (the buildup of lymph fluid in the soft tissues of the body), for which there is no cure.¹² Exposure to radiation is associated with long-term risks such as the development of leukemia (a cancer that affects the blood and bone marrow). In addition, chemotherapy regimens, particularly the anthracyclines, administered indiscriminately in varying doses using a wide range of protocols through the end of the 20th century have well-established cardiotoxicities.¹³

Screening as a National Obsession

Perhaps most remarkable in the story of breast cancer has been the intense—and, at times, obsessive—national focus on breast cancer screening. Routine breast self-exam (BSE), long a women’s health mantra, does not decrease mortality from breast cancer, nor does it find breast cancer at an earlier stage.¹⁴ “Early detection saves lives” practically became a national anthem, but unfortunately, it is not quite true. Evidence from randomized trials on the impact of screening mammography in saving lives is conflicted: It appears that the benefits of screening mammography in reducing mortality are modest at best.¹⁵

And there are harms associated with screening. Mammography does not prevent or cure breast cancer but has a high likelihood (25-50%) of false-positive tests, resulting in unnecessary testing, biopsies and anxiety.¹⁶ From a public health perspective, the harms and public health costs of screening mammography may actually outweigh the modest benefits of the intervention.

¹² Fortunately, this procedure had largely been replaced with sentinel lymph node biopsy in an attempt to address this harm. Yet, for patients with nodal involvement, lymphedema persists affecting 1 in 5 patients treated for breast cancer today. Gillespie TC, Sayegh HE, Brunelle CL, et al. Breast Cancer-Related Lymphedema: Risk Factors, Precautionary Measures, and Treatments. *Gland Surg.* 2018 Aug;7(4):379-403.

¹³ Volkova M, Russell R III. Anthracycline Cardiotoxicity: Prevalence, Pathogenesis and Treatment. *Curr Cardiol Rev.* 2011 Nov;7(4):214-220.

¹⁴ In 1980, the American Cancer Society (ACS) was recommending monthly self-breast exams to women starting in high school (for which there was no scientific evidence) and yearly mammograms to women over 50 (for which there was limited scientific evidence). In 1997, ACS changed its recommendation of yearly mammograms to include women 40-50 years old; in 2015, it modified its recommendation once again, raising the recommended age for annual mammograms to 45. Current recommendations are annual mammograms for women 45-54 years of age, “optional” mammograms for women 40-44 and the “option” of switching to a mammogram every other year for women over 54. Clinical breast exams are no longer recommended for breast cancer screening among average-risk women at any age.

¹⁵ Barratt A. Overdiagnosis in Mammography Screening: A 45 Year Journey From Shadowy Idea to Acknowledged Reality. *BMJ.* 2015 Mar 3;350:h867.

Baum M. 2013. Harms From Breast Cancer Screening Outweigh Benefits if Death Caused by Treatment Is Included. *BMJ.* 2013 Jan 23;346:f385.

Gøtzsche PC, Nielsen M. Screening for Breast Cancer With Mammography. *Cochrane Database Syst Rev.* 2011 Jan 19; (1):CD001877.

¹⁶ Nelson HD, Cantor A, Humphrey L, et al. Screening for Breast Cancer: A Systematic Review to Update the 2009 US Preventative Services Task Force Recommendation [Internet]. Agency for Healthcare Research and Quality (US). 2016 Jan. Report No.: 14-05201-EF-1.

B. The Business of Breast Cancer

Breast cancer has cost millions of lives and, at the same time, has cost billions of dollars.¹⁷ By any measure, breast cancer is a big business, and is also a huge economic burden. Anticancer drugs in the U.S. routinely exceed \$100,000 per year of treatment.¹⁸ The national cost for annual screening for privately insured women 40-49 years of age alone is \$2.13 billion per year.¹⁹ The cost of cancer care is high and only getting higher.²⁰

In 2018 alone, at least one billion federal dollars were invested to fund breast cancer research, and untold dollars were likewise spent by industry.²¹ This has been augmented by substantial philanthropic and private research funds.

Today, the enormous business enterprise of breast cancer is marked by large incentives and significant conflicts of interest among industry, health care institutions, doctors and researchers.²² In this context, unfortunately, ending breast cancer is not even a universally shared, singular goal.

C. The Politics of Breast Cancer

Like all social movements, breast cancer advocacy was built on the work of advocates who came before. In 1970, the publication of *Our Bodies, Ourselves* by the Boston Women's Health Collective inspired women to learn about their own bodies and exert some control over health care decisions. In 1974, First Lady Betty Ford spoke publicly about her own breast cancer diagnosis, empowering other women to do the same. During this time, journalist turned breast cancer advocate Rose Kushner fought to separate the one-step biopsy-mastectomy procedure, effectively changing the standard

¹⁷ Federal government investments have been the single largest source of funding. This began with the National Cancer Act of 1937, which created the National Cancer Institute (NCI), followed by the National Cancer Act of 1971, which resulted in the National Cancer Program having its own congressionally reviewed and approved annual budget. In 1992, the Department of Defense (DOD) Breast Cancer Research Program (BCRP) was launched as a result of NBCC's grassroots advocacy, and this program has received nearly \$3.8 billion in congressional appropriations as of 2020. CDMRP. "Breast Cancer." Last updated: May 1, 2020. Available at: <https://cdmnp.army.mil/bcrp/default>.

¹⁸ Medicare Part B Drugs and Oncology: statement of Mark E. Miller before the Subcommittee on Health, Committee on Ways and Means, U.S. House of Representatives, July 13, 2006. The median launch prices for new anticancer drugs increased each decade from \$100 per month of treatment in the 1960s to \$10,000 per month in 2007; these costs are even higher today.

Bach PB. Limits on Medicare's Ability to Control Rising Spending on Cancer Drugs. *N Engl J Med*. 2009 Feb 5;360(6):626-33. Erratum in: *N Engl J Med*. 2009 Feb 26;360(9):944.

¹⁹ Kunst N, Long JB, Xu X, et al. Use and Costs of Breast Cancer Screening for Women in Their 40s in a US Population With Private Insurance. *JAMA Intern Med*. 2020 Mar 23;180(5):799-801.

²⁰ It has been projected that the costs of cancer care to society would increase by 27 percent from \$124.6 billion in 2010 to \$157.8 billion in 2020 (assuming 2010 U.S. dollars).

Mariotto AB, Yabroff KR, Shao Y, et al. Projections of the Cost of Cancer Care in the United States: 2010-2020. *J Natl Cancer Inst*. 2011 Jan 19;103(2):117-28. Erratum in: *J Natl Cancer Inst*. 2011 Apr 20;103(8):699.

²¹ NIH Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC) Table. Published: February 24, 2020. CDMRP. "Breast Cancer." Last updated on: May 1, 2020. Available at: <https://cdmnp.army.mil/bcrp/default>.

²² Efforts to prevent conflicts of interest as a driving force in the biomedical and cancer fields have been largely ineffective. A case in point: Widely publicized news regarding then physician in chief at Memorial Sloan Kettering Cancer Center broke in late 2018 that he had failed to disclose millions of dollars he had received from companies connected to the breast cancer research and trials he was publishing on. Sadly, this was not an isolated case, and numerous reports both prior to and following this event, have demonstrated that profit motives and conflicts of interest remain strong in the cancer world.

Visco FM. Conflicts have killed trust in the system. Advocates must rebuild it. *The Cancer Letter*. 2018 Dec 14;44(46):10-13

Visco FM. "Financial Conflicts of Interest" (Letter). *The New York Times*. Published: September 13, 2018. Available at: <https://www.nytimes.com/2018/09/13/opinion/letters/doctors-conflicts-of-interest.html>.

of care for breast cancer.²³ She went on to question and challenge every orthodoxy in breast cancer treatment. Meanwhile, the AIDS movement of the early 1980s served as a powerful model for direct patient activism in the face of medical and governmental intransigence.

Around this time, women were creating breast cancer organizations devoted to awareness, individual empowerment and raising funds for research. This chapter of breast cancer advocacy was a fascinating combination of feminist self-help, scrappy grassroots organizing, corporate branding, medical sound bites and the emergence of biomedical research as “cause.” In 1982, the Susan G. Komen Breast Cancer Foundation was founded, and the mantra “early detection saves lives”—the notion that individuals can save their lives by getting screened earlier and more often—became its centerpiece. In 1985, pharmaceutical companies worked with the American Cancer Society to establish October as National Breast Cancer Awareness Month, with the stated goal of promoting mammography as the most effective weapon in the fight against breast cancer.²⁴

2. The National Breast Cancer Coalition Story

In 1991, a small group of women invited breast cancer groups from across the country to create a coalition of breast cancer organizations. The formation of a separate coalition would allow many breast cancer organizations to participate in political action with a single voice and targeted goals.²⁵

A. A New Kind of Advocacy

Since NBCC’s inception, our mission remains unchanged: to end breast cancer. Our goals to achieve that mission have been: 1) to make certain there is sufficient funding for meaningful research and support for the right clinical trials, 2) to ensure access to quality health care for all and 3) to advance the influence of trained advocates in all aspects of breast cancer. Our mission-driven strategy created a unique approach to breast cancer advocacy.

For NBCC, advocate involvement in science was never about individuals’ personal stories or advocating for individuals. We saw an entire system that needed to change, a system of incrementalism—often uncoordinated and siloed—that misaligned financial incentives and shunned the participation of “laypeople” in research—except, of course, as subjects.

We knew that our nation needed to invest more in breast cancer research, but we also knew that we needed more accountability and advocate involvement at every level of the research process. So when NBCC’s advocacy brought about the Department of Defense peer-reviewed Breast Cancer Research Program (DOD BCRP),²⁶ we spearheaded an unprecedented model of advocate involvement and innovative research.

²³ Robertson N. “A Woman’s Crusade Against ‘One-Step’ Breast Surgery.” *The New York Times*. Published: October 22, 1979. Available at: <https://www.nytimes.com/1979/10/22/archives/a-womans-crusade-against-onestep-breast-surgery-25000-have.html>

²⁴ Sulik G. 2011. *Pink Ribbon Blues: How Breast Cancer Undermines Women’s Health*. New York: Oxford University Press.

²⁵ NBCC’s structure is designed to make certain that its agenda is informed by the diversity that is breast cancer. Its board of directors is made up of diverse organizations from across the country, representing different perspectives, geographies and ethnicities. Each year, NBCC announces a call for priorities, asking its nationwide grassroots members to identify issues that should become priorities for NBCC’s policy advocacy. The only criteria are that the issues must be overarching, not focused on a narrow agenda and impactful in leading to the end of breast cancer. NBCC’s grassroots board then reviews all recommendations and sets NBCC’s policy agenda for the coming year.

²⁶ Since its inception in 1991, this DOD program has attracted more than 57,439 applications (through fiscal year [FY] 2018) and invested \$3.75 billion (through FY 2020) in innovative breast cancer research. CDMRP. “Breast Cancer.” Last updated on: May 1, 2020. Available at: <https://cdmrp.army.mil/bcrp/>.

To ensure that breast cancer advocates had the knowledge and confidence to be effective, NBCC created Project LEAD[®], an intensive science course for breast cancer advocates covering the basics of cancer biology, genetics, epidemiology, research design and advocacy. This in-depth and rigorous program provides a foundation of scientific knowledge that strengthens and empowers graduates as activists.²⁷

While many patient advocates were simply demanding “more care,” NBCC remained doggedly committed to evidence-based breast cancer policy, which requires asking hard and often very unpopular questions. The list of NBCC’s unpopular but evidence-based positions is a long one.²⁸ Perhaps the most contentious has been the holy grail of breast cancer: the mammogram. NBCC has long taken a stance, based on the best available evidence that population breast cancer screening is not warranted for women under the age of 50 and is questionable for older women.²⁹

Access to quality breast cancer care has always been core to NBCC’s mission. Channeling the outrage that low-income women were provided access to breast cancer screening that would find their cancers but not afford access to treatment, NBCC spearheaded an aggressive grassroots campaign that resulted in a law (Public Law 106-354) guaranteeing treatment to low-income, uninsured women screened and diagnosed with breast and cervical cancer.³⁰ Guaranteed access to quality care for all has been a public policy priority of NBCC since practically our inception. In 2010, NBCC endorsed and advocated for the passage and implementation of the Affordable Care Act, which marked important steps forward in access to quality health care for individuals with, and at risk of, breast cancer.

B. Why We Set a Deadline

By 2010, we had succeeded in creating a system of access to health care for *more uninsured women* increasing the amount of evidence-based information and treatment available, ensuring an *adequate level of funding* for research and creating a *national model of advocate involvement* in research. At this point, we decided that “more of the same” would not be effective; it was time for something bolder. So we set a deadline to know how to end breast cancer by January 1, 2020.

²⁷ Since 1995, more than 2,400 Project LEAD graduates have been trained in research advocacy, many of whom actively partner with researchers to design and implement research, evaluate research proposals and shape national research priorities. In a recent NBCC survey of Project LEAD advocates and their research-related advocacy work, significant percentages have participated as advocates in clinical trials and scientific peer-reviewed work, including the DOD Congressionally Directed Medical Research Program, and as advisers on practice guidelines panels, Institutional Review Board (IRB) projects and other research-related projects.

²⁸ For example, in the early 1990s, many patients were demanding bone marrow transplants for breast cancer treatment. NBCC argued for waiting for the results of the randomized trials, which unfortunately showed that patients given this treatment had no better outcomes than those getting the regular standard of care. BSEs were all the rage, but there is no evidence that a regimented monthly breast check reduces mortality, but it does appear to create more false positives, which means women face unnecessary anxiety and health interventions. These are just two of many examples.

²⁹ In testimony before Congress, in the media and in public outreach, NBCC called the public outrage against the science-based screening guidelines of the NCI in 1997 and the U.S. Preventive Services Task Force (USPSTF) in 2009 misplaced and based on emotion taking precedent over hard science and evidence. House Energy and Commerce Committee – Health Subcommittee, December 2, 2009; <http://www.breastcancerdeadline2020.org/get-involved/public-policy/testimony/December-2-2009-Testimony-Visco-House-Energy-Comm-Cmte.html>. We have often been the messenger of sobering explanations as to why the latest fads such as 3D mammography or artificial intelligence (AI)-assisted screening faded while breast cancer remained.

³⁰ This unique and unprecedented NBCC advocate-driven public policy effort resulted in the Breast and Cervical Cancer Treatment Act (Public Law 106-354) in 2000, which allowed states to receive federal funding to help cover the cost of treatment through Medicaid for low-income, uninsured women who had been diagnosed with breast or cervical cancer through the Centers for Disease Control and Prevention’s (CDC’s) Early Detection Program. This repaired an unconscionable flaw in the original screening program established as a result of the Breast and Cervical Cancer Mortality Prevention Act of 1990 (Public Law 101-354).

The research community appeared to believe that the tools ordinarily used to solve complex problems, such as coordination, collaboration and accountability, did not apply to breast cancer. We were not convinced. What if as Dan Sarewitz asks in his article “Saving Science,” the notion that scientific progress comes from “the free play of free intellects, working on subjects of their own choice, in the manner dictated by their curiosity” was simply wrong?³¹

What would it look like if we carved out a system devoted exclusively to ending breast cancer? What if we used tried-and-true strategies such as coordination, collaboration and accountability?

What would it look like if we carved out a system devoted *exclusively* to ending breast cancer? What if we used tried-and-true strategies such as coordination, collaboration and accountability? What if we looked beyond the traditional incremental approach of one gene, one pathway and one mutation at a time? NBCC brought together a diverse group of advocates and breast cancer experts to answer those questions. They concluded that, done right, these strategies could make all the difference.

Organizations generally avoid bold public deadlines because of the looming possibility of failure. Naturally self-serving and self-preserving, organizations can conflate the needs of the organization itself with its original mission. Every organization

wants to succeed. But NBCC is not like most organizations. Our mission from day one has been to end breast cancer—not to create more awareness, not to ensure more breast cancer funding, and certainly not to build a permanent breast cancer advocacy organization.

Deadline 2020 was provocative—that was the intention. And there was some backlash. Some complained that NBCC was overpromising, creating “false hope.” But Deadline 2020 was not a promise, and ending breast cancer is not a pipe dream. This deadline was a call to action, an invitation to do something bold and unprecedented.

Some suggested that setting a deadline should not be led by one advocacy organization. We agreed: Deadline 2020 was never about NBCC or any other organization; it was about marshaling our country’s incredible resources to end breast cancer.

Perhaps the most frustrating response from naysayers were some in the scientific community who found a deadline unbecoming of science because it is “not the way science works.” We understand better than anyone that deadlines are not “how science works.” That was the point. Deadline 2020® was a call to change how science works.

We were asked many times, “What if you fail?” By 2010, we had *already* failed. We failed our family and friends who we lost to breast cancer as well as the millions of others who have died of breast cancer. For NBCC, the question was never *what if we fail*, but *how will we succeed?*

³¹ Sarewitz D. “Saving Science.” The New Atlantis. Published Spring/Summer 2016. Available at: <https://www.thenewatlantis.com/publications/saving-science>.

3. Deadline 2020

A collaborative, deadline-driven mission approach to breast cancer had never been attempted. But examples of success in other fields suggested that it is often the lack of vision, willpower, accountability and leadership—not the level of knowledge or the science itself—that stymied progress.

A. The Vision

To know how to end breast cancer by 2020, NBCC envisioned transformational changes in three strategic areas: research, access and influence. We wanted to create a space for bold research approaches that would focus on the most

important ways to stop breast cancer from ever happening and stop it from causing death. We foresaw a fundamental change in the national focus on breast cancer, away from screening and awareness and toward an understanding of evidence-based health care and an appreciation for meaningful medical research. And we understood we needed leadership that would actually prioritize ending breast cancer and create global collaborations to harness the power of the public, scientists, and government to achieve that goal. We focused our efforts on three areas:

- **Research:** Facilitate collaborations in all areas of breast cancer research and minimize unnecessary competition.
- **Access:** Develop a global strategy to ensure that individuals with, and at risk of, breast cancer have access to information, quality care and scientific advances.
- **Influence:** Change the national conversation and mobilize the breast cancer advocacy community.

B. The Challenges

It has been quite the decade. In 2010, most of us would not have imagined our nation's current state of affairs. Deadline 2020 was launched two years after the greatest recession since the Great Depression knocked our economy off its feet, narrowing our nation's priorities; breast cancer has since been eclipsed by issues like immigration and tax cuts on the right and climate change and income inequality on the left. And now a pandemic.

There is no question that our country faces some existential threats that have nothing to do with breast cancer. But throughout this tumultuous decade, breast cancer continued to take its toll, claiming the lives of more than 42,000 individuals each year, in this country alone, and NBCC continued our mission-focused advocacy.

Leveraging Government Resources

When we launched the Deadline, we knew the federal government had to take on a leadership role in that effort. Unfortunately, even inexpensive, commonsense strategies for moving breast cancer research forward seemed to be too difficult for our leaders. For example, the federal government has *already* invested enormous resources that have resulted in the knowledge, tools and technologies

To know how to end breast cancer by 2020, NBCC envisioned transformational changes in three strategic areas: research, access and influence.

needed to end breast cancer. By reviewing the plethora of previous research and discoveries in the context of all the new information we have gleaned in the last decade, researchers have an opportunity to make new connections that might lead to breakthroughs. Toward this goal, NBCC initiated the Accelerating the End of Breast Cancer Act of 2015, which laid out a strategy for government involvement. This bill would have created a national commission to capitalize on federal and private investments *already made* in science and technology development and develop a plan to accelerate innovation in breast cancer.

NBCC did all that is possible to make this bill a reality, gaining 274 House and 54 Senate cosponsors, but the bill, which had extensive bipartisan support, fell into the political abyss of inaction and partisan politics. House leadership refused to bring it to the floor for a vote, despite many campaigns to accomplish that. National leadership to more fully leverage existing research and focus on real innovation is still sorely needed.

Shifting Values of Scientific Community

Shortly after the Deadline 2020 campaign was launched, *Nature*, a well-regarded scientific journal, criticized NBCC for what was termed a “misguided cancer goal.”³² Deadline 2020 was chided as “potentially harmful to the public trust that underpins the whole research enterprise.” We argued that public trust had been damaged more by the highly profitable industry that has emerged and brought only incremental improvements following many billions of dollars in public investments for more than the past 50 years into the so-called “research enterprise.” The status quo was working for many scientists, but very little was changing for people living with, and dying from, breast cancer.

Ten years later, *Nature* had a different take. A recent editorial celebrated the 50th anniversary of landing a person on the moon by offering advice to “earthshots”—those bold plans with audacious goals such as conquering cancer, addressing climate change or developing a new generation of antibiotics. This more recent editorial argues that to solve such profoundly important and complex challenges, we need not just money and expertise, but an unprecedented level of collaboration among universities, companies and governments; a reckoning of competing political ideologies; and a fuller recognition of the citizen’s voice.³³

We at the National Breast Cancer Coalition NBCC could not agree more. That was exactly the call to action NBCC issued to the scientific community in 2010. Fortunately, not everyone in the scientific community saw Deadline 2020 as a misguided goal. When a renowned genomic scientist was asked about setting a deadline, he summed up the thrust of the campaign: “I don’t know if we can end breast cancer in ten years, but I think we should try.” What if the entire scientific community had taken that approach? Where might we be now?

³² Nature. “Misguided cancer goal.” Published on: November 28, 2012. Available at: <https://www.nature.com/news/misguided-cancer-goal-1.11894>.

³³ Nature. “Cancer, climate, plastics: why ‘earthshots’ are harder than moonshots.” Published on: July 10, 2019. Available at: <https://www.nature.com/articles/d41586-019-02093-7>.

C. The Progress

Despite the many barriers we faced for Deadline 2020, and as a country during the past decade, the list of NBCC's accomplishments remains impressive.

Increased Access

Driven by a network of strong and well-educated advocates who understand that influencing public policy is one of the strategies to achieving the mission to end breast cancer, NBCC has made progress in improving access to quality breast cancer care:

- NBCC increased our advocacy focused on guaranteed access to quality health care for all. Our advocacy network worked hard to help get the Affordable Care Act through Congress, testifying before Congress on its importance. NBCC successfully pushed for the law to include lay advocates wherever important decisions are made.
- A number of clinical trials involved NBCC leadership and our grassroots network helping women access important trials.
- Most recently, the Metastatic Breast Cancer Access to Care Act has been a key legislative priority that would waive the 24-month waiting period for Medicare eligibility and the five-month waiting period for Social Security Disability Insurance (SSDI) benefits for individuals with metastatic breast cancer. This bill continues to garner strong congressional support.

Increased Influence

Deadline 2020 created unique opportunities to expand the influence of NBCC:

- President Bill Clinton stepped up as honorary chair of Deadline 2020, helping bring attention and support to the campaign.
- NBCC followed through on our Deadline Blueprint mandate to maintain transparency and accountability throughout the decade by publishing a series of status updates and progress reports that were distributed online and through national channels.³⁴
- Investment in national leadership was accomplished through the creation of annual National Leadership Summits and by significantly expanding the educational arm of NBCC, the Center for Advocacy Training.
- An Online Center for Advocacy Training was launched as well as a unique and challenging Advanced Project LEAD.
- The Project LEAD model was once again used as the basis for an unprecedented educational program for health journalists and editors of major women's publications.
- Media Project LEAD took place in New York City in 2011 with a curriculum on epidemiology, evidence-based health care and statistics, introduction to the biology of breast cancer and communicating health information.

NBCC advocates around the country have also implemented a range of public policy initiatives aimed at galvanizing public support around Deadline 2020:

³⁴ With generous funding by the Breast Cancer Fund of the National Philanthropic Trust, NBCC began its national Deadline grassroots effort by providing competitive grant awards to local advocacy organizations for their efforts to move beyond awareness to action.

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- More than 300,000 signatures were gathered and delivered to the White House in 2013, asking for President Obama's commitment to prioritize ending breast cancer.
 - Advocates mounted campaigns during the 2012 and 2016 election cycle demanding every congressional and presidential candidate endorse Deadline 2020.
 - In the 2018 midterm election, NBCC's campaign, End Breast Cancer: Vote! encouraged everyone who cared about breast cancer policy to vote and ask their elected officials to support NBCC's platform.

In addition, Deadline 2020 created opportunities for international collaboration:

- Breast Cancer Deadline 2020 was the centerpiece of a live worldwide study for scenario planning at Oxford University's Said Business School, which was attended by leaders from 40 major worldwide corporations.
- NBCC was invited to an international symposium on exemplary public health models in Qatar, during which NBCC's Project LEAD was highlighted as the worldwide advocate leadership model.
- Both the DOD and the Project LEAD programs have been used as models for several international efforts in advocate-led research collaborations and advocate research education. Notably, the Grand Challenge Program for Cancer in the United Kingdom (U.K.), a global community of researchers working on large unanswered questions in cancer, requires that advocates be integral members of the research teams. NBCC was asked to address its members on the success of our model.
- Founders of the U.K. version of British Project LEAD, *Voice*, were empowered by the Project LEAD model. British graduates of Project LEAD praised "... the scheme for developing their understanding of basic cancer biology and research study design, equipping them with the confidence, knowledge, and skills to contribute to advocate-driven, and advocate-oriented improvements in clinical research at both the local and national levels." Other such programs based on the Project LEAD model have been created in Germany, Canada and Japan.

Increased Research

Throughout the Deadline 2020 decade, NBCC advocates continued to spearhead support for innovative research:

- Each year, advocates mounted successful efforts to help secure annual funding for the Department of Defense peer-reviewed Breast Cancer Research Program. To date, it has attracted more than 57,439 applications (through FY 2018) and invested \$3.75 billion (through FY 2020) in early-stage innovative breast cancer research. Advocates also work with DOD research grantees to help advance the research agenda.
- International scientists joined a number of Deadline 2020 research collaborations, including the Artemis Project[®]. NBCC advocates partnered with Translational Research in Oncology (TRIO), a prestigious international clinical trials consortium, on several key trials.
- Project LEAD graduates played important roles in a number of clinical trial partnerships with industry, including trials of PARP inhibitors and CDK4/6 inhibitors. In all these trials, NBCC advocates were represented on each trial's Steering Committee and Data Safety Monitoring Boards, providing feedback and input on trial design, safety issues, ethics, and progress.

In addition to these specific research initiatives, and with Deadline 2020 spurring us on, we decided it was not enough to promote the kind of collaboration we envisioned; we needed to actually do it ourselves.

The Artemis Project®

Although NBCC couldn't possibly fund the scope of research needed to end breast cancer, we could at least model what mission-focused and truly collaborative breast cancer research looked like. We wanted to bring focus to two overarching questions that were not receiving sufficient attention and to address those questions in ways that were important to us. This is the research component of Deadline 2020, which we named the **Artemis Project** after the Greek goddess of hunting and the wilderness. We figured a fierce female goddess was just right for tackling such an audacious project. We recruited talented and innovative researchers, advocates and other key stakeholders that included scientific expertise ranging from immunology, medical anthropology, biophysics and genetics to molecular biology, biomedical engineering, informatics and clinical oncology. The Artemis Project is meant to complement our existing research work: our advocacy to continue the DOD BCRP, our training research advocates to help set the agenda, our clinical trials project and our collaborations with researchers on specific proposals.

When we came up with the idea for the Artemis Project, we were not certain if the caliber of scientists we wanted would be willing to have advocates set the agenda. We continue to be amazed at how willing many of them are.³⁵

We began with this challenge: What are the most important issues for the greatest number of people facing breast cancer? First, no one should ever have to get a diagnosis of breast cancer. And second, if they do, they should not die of it. In our Artemis Project, we decided to address this latter issue from a different perspective: There should be a way to prevent the cancer from spreading, which is ultimately what makes breast cancer fatal. Thus, our two Artemis Project priorities were established: **primary prevention** (How do we stop women and men from getting breast cancer?) and **preventing metastasis** (How do we stop them from dying of breast cancer?) From there, the group designed and began to implement research plans that focus on these two areas.

Primary Prevention: A Vaccine

We started the project with the bold idea of a preventive vaccine. While many in science, the media and advocacy looked on with mild and mostly dismissive amusement, we kept at it. Today, because of the Deadline 2020 campaign, we are just months away from a Phase 1 Safety Trial for a preventive vaccine. Our ultimate goal is to develop a safe and cost-effective vaccine that targets all major subsets of breast cancer, reduces the incidence of breast cancer and prevents death from breast cancer.

Stopping Deaths From Breast Cancer: Preventing Metastasis

If we cannot prevent breast cancer, can we prevent it from becoming lethal? Breast cancer takes lives when it spreads to other organs, when it becomes metastatic. In Artemis, we want to look at metastatic disease from a fresh perspective to achieve the goal of ending the disease. While we focus on existing metastatic disease through our work on clinical trials, the DOD BCRP,³⁶ and our education and training programs, our Artemis goal has been to complement that work, by focusing on the

³⁵ Visit the NBCC Website, www.stopbreastcancer.org, for a complete list of Artemis Project collaborators and reports of annual meetings.

³⁶ The DoD BCRP engages advocates at every level of decision-making, identifies overarching issues that are key to metastatic breast cancer, and funds a broad portfolio of metastatic breast cancer research. According to a 2018 NBCC advocate-led analysis, presented at the 2019 San Antonio Breast Cancer Symposium, upwards of 57 percent of DOD BCRP funds allocated in 2016 supported metastatic breast cancer research. Abstract P4-15-03: An analysis of the National Institutes of Health (NIH) breast cancer research portfolio and the Department of Defense (DOD) breast cancer research program (BCRP) funding for metastatic breast cancer research in fiscal year 2016. ABCS19-P4-15-03 Published February 2020

process and prevention of metastasis. We decided to initially address tumor dormancy. Why and how do breast cancer cells lie dormant for years and then reemerge? Can we figure that out and intervene to stop it? Can the immune system play a role? Some Artemis Project participants have begun testing how the immune system interacts with dormant disseminated tumor cells—those cells that migrate from the primary tumor site. Once it has been established that the immune system does play a role in keeping these disseminated tumor cells quiet, they will identify the key immune cells that are involved.

The Artemis Project collaboration also agreed that it was a priority to determine the genomic and genetic makeup of breast cancer that will progress to metastasis. Toward this goal, in one subcomponent of the Artemis Project, we partnered with DNA.Land, which has enabled NBCC to crowdsource genomes from more than 160,000 individuals and will ultimately allow researchers to ask critical questions about breast cancer development, breast cancer recurrence and metastatic disease.

A New Frontier for Collaborative Research

NBCC's Artemis Project collaboration has helped to catalyze collaborative ways of conducting research and provided a laser focus on the types of research questions that need to be asked to make significant advances in the way we think about preventing breast cancer and breast cancer deaths. As one researcher explains regarding the Artemis Project and Deadline 2020, "There is now a sense of possibility—and I think the Deadline has played a role in this—as the science has moved forward with some promising results related to immunotherapy, there is more hope and focus. Ten years ago, this was pie in the sky—now many people think it is possible."

Prior to Deadline 2020, the scientific community had not focused on metastasis research as a major priority or on ending breast cancer as a mission, but now, as one advocate describes it, "The whole scientific community is revving up. It feels like a perfect storm; NBCC's push to focus on actually ending breast cancer has helped changed the questions in the larger community."

Impact on Scientists and the Scientific Process

We are proud of our progress and process. The Artemis Project innovative model of cooperation enables individuals aligned toward a common goal to interact and engage with others with complementary talents, skills and expertise. In contrast to more conventional strategies, the Artemis Project enables advocates, physicians, scientists and other stakeholders to interact and develop activities that collectively contribute to a highly complex strategic plan that would ordinarily be supported by significant financial resources or a large corporate organization.

Artemis Project participants describe the project as "completely different" from other projects. As one explains it, "The Artemis Project is the boldest, far-reaching, 'impossible' initiative. When you're being challenged that much you feel a responsibility to do the impossible. There's nothing like Artemis." Part of it is the people in the room: The Artemis Project brings experts together who would otherwise have never met. But it is also the sense of urgency and shared goal set by Deadline 2020. "There is a nearly

NBCC's Artemis Project collaboration has helped to catalyze collaborative ways of conducting research and provided a laser focus on the types of research questions that need to be asked to make significant advances in the way we think about preventing breast cancer and breast cancer deaths.

universal personal investment in the project,” another researcher explains, “and so personal agendas are set aside to really hone in on the questions being asked that, in and of themselves, are very unusual.”

One scientist describes how the traditional scientific process does not place much emphasis on the impact on people and how a different model of research can make a real difference:

“Truthfully, the end goal for most scientists is publishing a paper and then getting the grants to continue the work in order to publish another paper ... What’s so special about Artemis is people working together who would never be working together under other circumstances.”

Collaboration is not always easy. One researcher describes how some calculations change in a mission-driven collaboration:

“By accelerating the urgency, the Deadline forced all of us to get along ... staying very focused on the results ... and moving your ego completely out of the picture.”

The mission-driven focus of the project keeps everyone’s eye on the prize. One researcher describes the Artemis Project as a “focused think tank.”

“In most think tanks, people go in different directions, but here we have very clear constraints. We still expand and go off on tangents, but there are two themes that keep it grounded. It’s more of a greenhouse to identify the steps that will take us to a solution.”

Other researchers found the deadline shifted their thinking:

“When people heard more about Deadline 2020 and really challenged themselves to take on that goal—maybe knowing that we might not actually cure breast cancer—but what if we tried? It meant we’ve pushed ourselves to be a little more creative, a little more impactful with the work we’re doing. Just imagining that we could do this is the first mark of success.”

What about fear of failure? Or creating false hopes? These scientists dismissed those concerns. One explains that he “fully believes in setting really ambitious goals so that even if you fall short, you still accomplish a lot. We don’t want people to fall into the sense that this can be done tomorrow when it needs to be done today.” Advocates also find the mission-focused collaboration inspiring. One long-time advocate noted that:

“My involvement with researchers is now much more focused and precise— instead of general relationships, we are focusing and prioritizing. We are all much more focused on results.”

Advocates who embraced the deadline were gratified to see more and more researchers come into the fold. According to one advocate, “Some who completely discounted the deadline are now joining in and appreciating the laser focus on ending breast cancer.”

Increased Advocate Involvement

It has been gratifying to see a transformation of the entire health care research process. Engaging advocates in the process of medical research is now commonplace.³⁷ New models of advocate-led collaborations and advocate-researcher partnerships are encouraging cross-disciplinary innovation and introducing a new level of accountability. In Canada and Europe, among others, national agencies promote advocate-identified priorities and improved patient outcomes, achieved through a multidisciplinary approach. In England, there is now a Patient Led Research Hub (PLRH) that supports research ideas as proposed by patient organizations, providing resources and expertise in research design and delivery.³⁸

Advocates have seen the difference. They report being contacted by researchers more often, feeling more respected in the process, and being more willing to speak up. Researchers are introducing advocates to their graduate students to encourage future involvement and advocates are recruited at earlier stages of the research process for input.

Since the launch of Deadline 2020, there has been a seismic shift in acceptance of advocates' involvement and collaboration in research.

Since the launch of Deadline 2020, there has been a seismic shift in acceptance of advocates' involvement and collaboration in research. An issue we need to address moving forward is the effectiveness and independence of a number of those advocate collaborations. Advocates must be trained, educated, and free from conflicts of interest that might interfere with their primary duty, which is to the broader constituency they represent—individuals at risk of or with breast cancer. We have seen too many instances of “astroturfing,” rather than authentic grassroots advocacy, and advocates who are chosen by and beholden to industry and institutions; who are not capable of

fully participating; who are there to advance their own personal agenda; or whose loyalty is to their resume, rather than ending breast cancer.

This is why NBCC educates and trains advocates in the biology, science and research methodology of breast cancer. Advocates must have the judgment and skills needed to critically analyze information in order to speak on behalf of others and maintain their integrity and objectivity. This is a critical ingredient to ensuring that advocates represent the right constituency and are comfortable with the language and concepts of science and unafraid to challenge the status quo.

³⁷ Prior to 2010, the DOD BCRP—a product of NBCC's early grassroots advocacy—was one of the only programs that engaged advocates in any meaningful way in defining the direction of research.

³⁸ Mader, LB, Harris T, Kläger S, et al. Inverting the patient involvement paradigm: defining patient-led research. *Research Involvement and Engagement*. 2018;4.21:1-7.

New Public Focus

Deadline 2020 was intended to know how to end breast cancer and to shift the public dialogue about breast cancer from awareness and screening to prevention and saving lives, and over the past decade, this has happened in significant ways. In many dozens of interviews with both advocates and researchers,³⁹ there is a noted and much-welcomed shift away from the relentless commercializing of breast cancer. As one advocate puts it, “There is a finally greater recognition that breast cancer is not all about pink ribbons.”

Another describes progress in “dismantling this notion that early detection is some kind of cure. There always has been—and still is—confusion between early detection and prevention. That mindset is not completely gone, but compared to ten years ago, we are in a much better place.” Many advocates see less emphasis on annual mammography in their communities and, as one put it, “Finally! No more talk about breast self-exams!” Quite a few are seeing more evidence-based questioning that “early detection saves lives.” Meanwhile, general public awareness of metastasis (the spread of breast cancer, which can be lethal) has increased significantly. The most aggressive treatment is no longer assumed to be necessarily the “best” treatment, and second opinions are more widely accepted.

New National Priorities

The shift in the national focus and funding is now reflective of the goals and efforts of Deadline 2020. With advocate influence, the DOD BCRP, for example, recently developed priorities that emphasize immune approaches, primary prevention and metastasis.⁴⁰

³⁹ Interviews were conducted mostly in the second half of 2018.

⁴⁰ Investigators applying to the DOD BCRP are asked to address the following overarching challenges:

- Prevent breast cancer.
- Identify what makes the breast susceptible to cancer development.
- Determine why some but not all women get breast cancer.
- Conquer the problems of overdiagnosis and overtreatment.
- Revolutionize treatment regimens by replacing interventions that have life-threatening toxicities with ones that are safe and effective.
- Identify what drives breast cancer growth and determine how to stop it.
- Distinguish aggressive breast cancer from indolent cancers.
- Determine why and how breast cancer cells lay dormant for years and then reemerge as well as determine how to prevent this recurrence.
- Identify why some breast cancers become life-threatening metastases.
- Eliminate the mortality associated with metastatic cancer.

CDMRP. “Breast Cancer.” Last updated on: May 1, 2020. Available at: <https://cdmrp.army.mil/bcrp/>.

4. Where We Go From Here

NBCC does not give up. Breast cancer remains, so we fight on. We will continue to press for the systematic changes needed to end breast cancer.

- **Primary Prevention. Preventive Vaccine.** Through our Artemis Project, we will fulfill our preventive vaccine development plan, beginning with a Phase I trial in 2020. Concurrently, we intend to refine Phase II plans, formalize intellectual property rights and investigate additional targets for the vaccine. We will leverage our trained grassroots network to help with trials and all outreach.
- **Primary Prevention. Beyond a Vaccine.** We will expand our primary prevention work and deepen plans begun at Artemis Project meetings investigating other avenues for stopping women and men from getting breast cancer in the first place.
- **Metastasis Prevention.** Our preventing metastasis work will continue with an emphasis on tumor dormancy and moving forward with innovative technology approaches. We will continue to expand our efforts to engage scientists and others beyond the world of biomedical research to focus on our goal of making certain no one gets lethal breast cancer.
- **Innovative Research Collaboration.** Because the Artemis Project has been successful on many levels, we want to ensure its continuation. We will devise new infrastructure that will result in a virtual collaboration institute.
- **International Advocate Leadership.** To end breast cancer, the worldwide advocacy community must take an even greater leadership role in research and policy. To that end, we will implement strategies to engage international advocates in science and policy leadership and develop projects led by advocates to complement ongoing research that meets our goals.
- **Advocate Collaboration in Clinical Research.** Strategies must help advocates focus on clinical trials that are meaningful and regulations that are designed to save lives. Our work beyond primary prevention and prevention of metastasis will expand, as our support for policy approaches, research funding, clinical trials and education and training will continue to encompass all aspects of breast cancer and all stages.
- **Advocate Education.** Our science education and training programs, especially Project LEAD, will remain the gold standard for advocacy. Going forward, we will significantly expand our programs and strategies to accommodate larger numbers of advocates and the increasingly complex science and policy issues we confront.
- **Public Policy Advocacy.** We know that our public policy work must continue, and we will expand our strategies beyond Congress and federal legislative approaches. Our intent is to look at state-focused policies, and also regulatory issues that will move us closer to ending breast cancer and saving lives. We will design and push forward legislation that incorporates our Framework and Quality Care Principles to advance the dialogue and achieve Guaranteed Access to Quality Healthcare for All.

We will work to fulfill our mission by designing new approaches that will end breast cancer, implementing lessons learned throughout the Deadline 2020 campaign, continuing to bring urgency to our mission and leveraging our successes. We will continue to collaborate with creative problem solvers, and we will continue to call out inefficient or ineffective breast cancer strategies and policies.

Conclusion

In any social movement, each advocacy organization plays a different role. In breast cancer, NBCC galvanizes and leads organizations across the country and thousands of individuals to change the systems of research, access and influence to end breast cancer. We are activists who tell the truth about breast cancer, upend the status quo when needed, empower survivors, and set the research agenda.

NBCC's role has not always been an easy one. Refusing to advocate for access to unproven interventions, severely limiting our acceptance of pharmaceutical funding, challenging national screening recommendations, questioning the priorities of the breast cancer research community, criticizing the drug approval process and speaking out about conflicts of interest and drug pricing—none of this made NBCC popular. Yet, no funding pressures, political expediency, public opinion or even pressure from other advocacy groups has shifted our singular focus. At times, this stoked controversy. But it is also why so many scientists, health care providers, policy-makers and advocates are part of the NBCC family.

Recognizing that public policy plays a role in all aspects of breast cancer, NBCC made it a political issue, leading a vast grassroots network of advocates focused on a strategic policy agenda. We brought about more than \$3.75 billion in funding for the Department of Defense Breast Cancer Research Program, influenced the process of research, created systems of access to health care for the uninsured, and pushed support for expanded health care access for everyone and for policies to ensure advocate involvement at all levels of breast cancer.

We changed the way research is done, and through our flagship Project LEAD program, formed a new network of educated and trained advocates to influence science and health care.

None of that will change. NBCC advocates will continue to shape public policy on the state and federal level by setting a meaningful agenda, participating in legislative, scientific, and regulatory decisions, and providing a critical analysis of breast cancer information.

We will continue to launch new models of research and create a space for bold ideas and collaborative research through the Artemis Project. We are now just months away from a Phase 1 Safety Trial for a preventive vaccine, and Artemis scientists and advocates will continue to concentrate on our goal to develop a safe and cost-effective vaccine that targets all major subsets of breast cancer, and reduces the incidence of breast cancer, and on new strategies to understand and intervene in metastasis and prevent deaths from breast cancer.

Until breast cancer ends, NBCC will continue to stand up for the truth, setting the record straight wherever we see misinformation. We will lead the research that's making the biggest impact and share progress honestly. And we will rally and train others to join the fight.

Because we have one mission and one mission only: to end breast cancer.



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