

**National Breast Cancer Coalition**

The  
**Breast  
Cancer  
Deadline**

**2020**

Breast Cancer Deadline  
**Why Now?**

*September 20, 2010*

[BreastCancerDeadline2020.org](http://BreastCancerDeadline2020.org)

## Summary

The world of breast cancer has lost its sense of urgency to end the disease. It is time for a radically new approach. “More of the same” will not be effective; additional funding and time can only be used fruitfully if efforts are part of a larger strategic plan focused *exclusively* on the one goal of eradicating breast cancer.

This effort will require a critical look at research and healthcare priorities, financial incentives, funding mechanisms and advocacy efforts. It will require a concentrated strategy to expand quality, evidence-based care. It must embrace unprecedented coordination, information sharing and accountability. It will require individuals and institutions to cooperate in new ways and to an extent never before considered. Vision, urgency, unwavering focus and creative collaboration under true leadership will be the key ingredients for success.

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

The National Breast Cancer Coalition (NBCC) is setting a deadline: End breast cancer by 2020. Breast Cancer Deadline 2020. It is time.

Deadlines can make the impossible possible. Putting a man on the moon was impossible. Curing polio was impossible. Eradicating small pox was impossible. What seems unimaginable can become reality with a deadline, strong leadership, strategic vision, and a culture of innovation. These ingredients are available to us right now, and now is the time to begin.

**NBCC is doing more than just setting a deadline. We have a plan of action to get there, with new collaborations and catalytic approaches to solve overarching challenges in breast cancer.**

No more “it can’t be done.” We will move to a strategic plan that harnesses scientific creativity, removes barriers, and inspires collaborative, innovative achievement. With a national commitment and a decade of unparalleled focus, we will end breast cancer.

## 1. Breast cancer has been, and continues to be, a relentless killer.

First identified by the Egyptians more than 3500 years ago, breast cancer is an ancient, intractable disease. In 460 B.C., Hippocrates described breast cancer as a systemic malady involving many parts of the body, and believed surgery would be of no benefit. But in the 1700s physicians began to view breast cancer primarily as a localized disease, leading to the practice of surgery to remove the tumor. In the mid-1800s William Halstead popularized the radical mastectomy, which doctors performed (with variations) for the next 100 years. By the 1950s, it was thought cancer grew in a very orderly manner. The cancer started very small and gradually grew larger. Doctors believed that if you could remove enough tissue in the area of the tumor, you could cure women.

But surgery was often unsuccessful, and some physicians began to circle back to the view that the disease might be systemic from the beginning –that cancer cells were floating throughout the body in the circulatory system. Chemotherapy, hormonal therapy, and radiation were added to supplement treatment with surgery. By the mid-1980s, breast-conserving surgery followed by radiation or chemotherapy was found to be as effective as mastectomy<sup>1</sup>.

Views on the nature of breast cancer have come full circle since Hippocrates' time and treatments have been adjusted to reflect current thought. But how much progress has been made in reducing incidence and mortality from the disease? Where do things stand today?

By any standard, we have not made adequate progress. **Despite years of campaigns to raise awareness, ever expanding screening programs, increased fundraising efforts and research, breast cancer incidence and mortality have not changed significantly.** Worldwide, breast cancer is the most frequently diagnosed cancer in women and the leading cause of cancer death among women.<sup>2</sup> The incidence of the disease is increasing and, despite tweaks in treatment regimens over the years and a few real advances, there has not been a dramatic change in mortality. Approximately 1.3 million women will be diagnosed with breast cancer this year, and more than a half million women will die from the disease. By 2030, with no major changes in prevention or treatment, it is estimated that close to 800,000 women will die each year from breast cancer.<sup>3</sup>

In the United States, the chance of a woman developing breast cancer during her lifetime has increased from about 1 in 11 in 1975 to 1 in 8 today.<sup>4</sup> U.S. breast cancer mortality has been declining but only slightly<sup>5</sup>. In 1991, in the United States, 117 women died of breast cancer every day. In 2010, that number is 110. If we continue making progress at the current rate, it will take more than *500 years* to end breast cancer.

The pain and suffering caused by breast cancer are immeasurable, but some aspects of the costs have been quantified. For example, the National Cancer Institute has estimated that breast cancer care in 2006 cost Americans \$13.9 billion. We spend about \$3.3 billion a year on mammograms.<sup>6</sup> In terms of lost productivity, breast cancer cost the country \$12.1 billion.<sup>7</sup>

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1 American Cancer Society, History of Cancer, 2010

2 BMJ 2010; 341:c3620. <http://www.who.int/mediacentre/factsheets/fs297/en/>.

3 World Health Organization projections of the global burden of disease including cancer: 2002-2030 [http://www.who.int/healthinfo/global\\_burden\\_disease/projections/en/index.html](http://www.who.int/healthinfo/global_burden_disease/projections/en/index.html)

4 SEER data at <http://seer.cancer.gov/statfacts/html/breast.html>

5 Between 1998-2007, the rate decreased 1.9% per year. The rate of decline varied by race. <http://seer.cancer.gov/faststats/selections.php?#Output>

6 About \$3.3 billion was spent on mammograms between November 2008 and November 2009, according to the American College of Radiology. WSJ Health Industry November 17, 2009, 11:16 A.M. ET Breast-Screening Advice Upended.

7 Cancer Trends Progress Report 2009-10, National Cancer Institute

These are not mere statistics, they represent millions of lives. These losses are unacceptable.

## **2. The lack of progress is not due to insufficient resources for research.**

In 1971 when President Nixon announced his “War Against Cancer,”<sup>8</sup> breast cancer was poorly understood and generally neglected by the scientific research community. Since then, billions in public funding, private investment and charitable contributions have been directed toward breast cancer. NBCC has been a model for other disease specific advocacy groups because of its successful advocacy resulting in increased federal funding for breast cancer research.<sup>9</sup>

Since 2001, the National Institute of Health has spent roughly a half-billion dollars each year on breast cancer research.<sup>10</sup> In addition, there is a peer-reviewed breast cancer federal research program that is specifically designed to encourage innovation.<sup>11</sup> Administered by the Department of Defense (DOD), the Breast Cancer Research Program (DOD BCRP) was established and is maintained as a direct result of NBCC grassroots efforts.<sup>12</sup> This program has allocated over \$2.5 billion to peer-reviewed breast cancer research since 1992.<sup>13</sup>

Private organizations also provide significant levels of support for breast cancer research in the United States. The largest among them is the Susan G Komen for the Cure (Komen), which has spent close to \$450 million on research since 1982.<sup>14</sup> They are not alone. The current breast cancer research portfolio of the American Cancer Society (ACS) is \$118.1 million; most of these projects extend over several

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**8** In January 1971 in his State of the Union Address, President Nixon announced an unprecedented national campaign against cancer: “... The time has come in America when the same kind of concentrated effort that split the atom and took man to the moon should be turned toward conquering this dread disease. Let us make a total national commitment to achieve this goal.” <http://thenewnixon.org>

**9** <http://www.cancer.gov/cancertopics/factsheet/NCI/research-funding>.

**10** <http://report.nih.gov/rcdc/categories>

**11** In 1992, the Office of the Congressionally Directed Medical Research Programs (CDMRP) was born from a powerful grassroots effort led by the NBCC that convinced Congress to appropriate funds for breast cancer research. This enabled a unique partnership among the public, Congress, and the military. Created within the U.S. Army Medical Research and Materiel Command to manage these critical funds, it is known as the Department of Defense (DOD) Breast Cancer Research Program (BCRP). Breast Cancer Program Booklet <http://cdmrp.army.mil/bcrp/default.shtml>

**12** DOD describes the genesis of the program as a direct result of NBCC advocacy: “The DOD BCRP was established in FY92 by Joint Appropriations Conference Committee Report No. 102-328, which provided \$25M for research on breast cancer screening and diagnosis for military women and family members. In 1993, grassroots advocates led by the National Breast Cancer Coalition influenced public policy, which led to a FY93 congressional appropriation of \$210M for peer-reviewed breast cancer research.” <http://cdmrp.army.mil/pubs/factsheets/bcrpproghistory.shtml>

**13** <http://cdmrp.army.mil/bcrp/default.shtml>

**14** Susan G. Komen for the Cure website <http://ww5.komen.org/ResearchGrants/GrantPrograms.html>

years.<sup>15</sup> Between 1992 and 2009, the Avon Breast Cancer Crusade awarded more than \$640 million.<sup>16</sup> And since 1993 the Breast Cancer Research Foundation has invested more than \$250 million.<sup>17</sup> This list goes on.

The pharmaceutical industry is certainly no longer neglecting breast cancer. There are more than 60 drugs currently approved for breast cancer by the Food and Drug Administration (FDA); this does not include the many drugs used “off label.”<sup>18</sup> The Pharmaceutical Research and Manufacturers of America (PhRMA) reports that currently 106 medicines for breast cancer are “in the pipeline.”<sup>19</sup> According to the NCI clinical trials website, more than 1500 breast cancer clinical trials are currently recruiting patients, the vast majority of which are looking at combinations and different doses of existing drugs.<sup>20</sup>

In terms of dollars available for research and the sheer number of drugs and other interventions available, there has been great success, but of course quantity is no measure of true success. **The question is impact: what has 40 years and billions of dollars produced?**

### **3. Our understanding of breast cancer has increased dramatically, but for people facing breast cancer, very little has changed.**

The last 40 years of research has generated a new understanding of basic biological processes important in breast cancer.<sup>21</sup> We now know that breast cancer is not one disease, but many. We know that breast tumors do not all grow at the same rate or spread in the same way, and it is not the size that determines the aggressiveness of breast cancer but the tumor biology and microenvironment. Some breast cancers are small, found early, and yet are deadly. Some are fast growing. Some grow slowly, are found by mammograms and are treated, but would never have been life threatening.<sup>22</sup> Each subtype of breast cancer has distinct biological features and responses to therapies.

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**15** American Cancer Society 2010 <http://www.cancer.org/Cancer/BreastCancer/MoreInformation/how-is-acis-involved-in-breast-cancer-research>

**16** Avon Foundation Accessed 09-14-10. <http://www.avonfoundation.org/financials.html>

**17** Breast Cancer Research Foundation website <http://www.bcrfcure.org/index.html>

**18** FDA no longer allows a search by condition to view approved drugs. Drugs.com lists 74 drugs for varying aspects of breast cancer. Accessed 09-14-10.

**19** PhRMA Report Medicines in Development for Cancer 2009

**20** An NCI Clinical Trials search finds 1,487 trails about female breast cancer and 225 about male breast cancer. Accessed September 13, 2010.

**21** Key areas of research include hormonal and growth factor regulation of breast cell proliferation, cell cycle regulation, and the processes that control development and differentiation. Charting the Course: Priorities for Breast Cancer Research Report of the Breast Cancer Progress Review Group NCI 1998

**22** The notion that “more screening is better” ignores the very real harms of over-diagnoses and over-treatment. More aggressive screening results in discovering more women with tumors that never would have caused symptoms or death due to breast cancer. These women, nonetheless, often undergo extremely invasive and painful treatment.

Most scientists believe that breast cancer is caused by both inherited and somatic mutations in a specific subset of genes. And we have identified additional risk factors for breast cancer.<sup>23</sup> There is also a growing recognition that cancer does not grow in isolation but is impacted by its immediate environment. Evidence is growing that many factors that impact women and their bodies may also impact cancer and its response to treatment. There are environmental factors, factors that affect energy balance and obesity, and factors that influence immunity and the tumor's environment within the body.

But the painful truth is that, for people facing breast cancer, very little has changed. And some of the changes are not necessarily for the better. For example, routine mammographic screening is now the accepted standard for early detection. But evidence of actual mortality reduction is conflicting and continues to be questioned by scientists, policy makers and members of the public. If mammography has had any impact on mortality, it is certainly a very small one.<sup>24</sup>

Breast-conserving surgery (lumpectomy) followed by local radiation therapy has become an option for many women with breast cancer.<sup>25</sup> But most women diagnosed with breast cancer, and many diagnosed with precancerous ductal carcinoma in situ (DCIS), still have some kind of surgery, regardless of whether their particular situation was life threatening.

As we learn more about breast cancer subtypes, evidence grows that many drugs benefit a small group of women, yet they are given to all. Chemotherapy drugs are often added to treatment regimens without a great deal of evidence of benefit. When longer-term evidence indicates benefit is limited

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**23** Risk factors include: older age, genetic factors, family history of breast or ovarian cancer, long menstrual history, nulliparity (having no children), older than 30 years of age at first full-term pregnancy, daily alcohol consumption, use of combined postmenopausal hormone therapy (PHT), postmenopausal obesity, and ionizing radiation. Factors that decrease a woman's risk of breast cancer include breast-feeding and physical activity (exercise). Recently, higher breast density has been shown to be strongly associated with the risk of breast cancer. <http://www.cancer.gov/cancertopics/factsheet/risk/estimating-breast-cancer-risk>. Note these factors account for only a small percentage of breast cancer cases. Why one person develops breast cancer and another does not, why some breast cancer is fatal and other breast cancer seems to regress and even disappear— these crucial questions remain a mystery.

**24** A 2006 Cochrane Collaboration systematic review found that screening mammography decreases the risk of death from breast cancer by about 15% in relative terms, or 0.05% in absolute terms, and that throughout a ten-year period, for every 2000 women screened, one death from breast cancer will be prevented but ten healthy women will undergo unnecessary diagnostic procedures and treatment with the attendant toxic effects. Gotzsche PC, Nielsen M. Screening for breast cancer with mammography. Cochrane Database of Systematic Reviews 2006, Issue 4. Art. No.: CD001877. DOI: 10.1002/14651858.CD001877.pub2. A recent article by Esserman, et al. in the October 2009 issue of JAMA continues to highlight the fact that screening mammography has not been shown to significantly decrease the number of aggressive or later-stage breast cancers. Esserman L, Shieh Y, Thompson I. Rethinking screening for breast cancer and prostate cancer. JAMA 2009 Oct 21; 302(15): 1685-92.

**25** A recent study indicated that (in one area of the country) mastectomy rates are on the rise. The cause of this shift is not yet clear. National Cancer Institute Bulletin July 28, 2009 • Volume 6 Number 15

and harm exists, existing treatments are rarely removed from regimens, regardless of the strength of evidence against their use. For example, many women diagnosed with invasive breast cancer of different subtypes continue to receive anthracyclines, though evidence shows that the drugs may only provide incremental benefit to a small group of patients, and could be replaced with a less toxic substitute.<sup>26</sup>

Our goal must be to save lives, yet new drugs are approved without evidence that they increase survival. The Food and Drug Administration (FDA) began approving drugs based on what are called “surrogate endpoints” in 1992.<sup>27</sup> These endpoints were meant to be a surrogate for increased survival, but that has not been the case. For example, in 2008, FDA gave fast-track approval to bevacizumab for the treatment of metastatic breast cancer, and a pharmaceutical company now brings in over \$1 billion in revenues from sales of the drug for breast cancer treatment each year.<sup>28</sup> But approval was given based on a single study showing modest improvements in progression free survival<sup>29</sup> and no improvement in overall survival or quality of life.

One hard-won success has been the development of more targeted breast cancer treatment aimed at treating the tumor alone, and sparing the rest of the body from the toxicity of traditional chemotherapy. A targeted treatment, trastuzumab, was developed for the 18-20% of women whose tumors overexpress human epidermal growth factor 2, or HER2. However, even this success story is qualified. The drug does not work for many women with HER2+ tumors<sup>30</sup> and where it does work, resistance often builds up within a year or two.<sup>31</sup>

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**26** <http://www.knowbreastcancer.org/controversies/anthracyclines/>

**27** In 1992 FDA instituted the Accelerated Approval regulation, allowing earlier approval of drugs to treat serious diseases, and that fill an unmet medical need based on a surrogate endpoint. A surrogate endpoint is a physical sign or laboratory finding used in clinical trials that may not itself be a direct measure, but one that is considered reasonably likely to predict therapeutic benefit and a clinically meaningful outcome, such as survival. However, there are few “true” surrogates, and it is crucial to note that a treatment that delays tumor growth and cancer progression may not actually lengthen survival.

<http://www.knowbreastcancer.org/controversies/antiangiogenesis/>,  
<http://www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/SpeedingAccessToImportantNewTherapies/ucm128291.htm>

**28** Bloomberg.com Roche May Lose \$1 Billion a Year on Avastin Change  
<http://www.bloomberg.com/news/2010-07-20/roche-s-avastin-fails-to-win-u-s-advisory-panel-backing-for-breast-cancer.html>

**29** Progression-free survival is the length of time during and after treatment in which a patient is living with a disease that does not get worse. It may be used in a clinical study or trial to help find out how well a new treatment works. Also called PFS. <http://www.knowbreastcancer.org/resources/glossary/>

**30** Use of Chemotherapy plus a Monoclonal Antibody against HER2 for Metastatic Breast Cancer That Overexpresses HER2. Dennis J. Slamon, M.D., Ph.D., Brian Leyland-Jones, M.D., Steven Shak, M.D., Hank Fuchs, M.D., Virginia Paton, Pharm.D., Alex Bajamonde, Ph.D., Thomas Fleming, Ph.D., Wolfgang Eiermann, M.D., Janet Wolter, M.D., Mark Pegram, M.D., Jose Baselga, M.D., and Larry Norton, M.D. N Engl J Med 2001; 344:783-792 March 15, 2001

**31** Trastuzumab: mechanism of action, resistance and future perspectives in HER2-overexpressing breast cancer. <http://annonc.oxfordjournals.org/content/early/2007/01/17/annonc.mdl475.full>

Researchers and the media often celebrate small accomplishments. We have been conditioned to believe that a drug that may extend life a few months is a breakthrough, that a 2% reduction in mortality is promising, that tumor regression or stabilization are cause for celebration, even though at that point there is no way to determine if anyone's life was actually prolonged. We have settled for these limited, incremental changes along with the platitude "early detection saves lives" for too long.

**Our goal is not more treatment; our goal is to make treatment unnecessary.** We seek to prevent the disease altogether and avoid the treatments that themselves can be disfiguring and lead to morbidity and mortality. While the list of therapeutics continues to lengthen, there is little emphasis on prevention of the disease and strategies for understanding how to intervene in a high risk or healthy population, including the role of the environment in the development of breast cancer.

#### 4. More of the same will not end breast cancer.

**More than 40 years and billions of dollars have not ended breast cancer. It has, however, created a robust cancer industry that thrives on raising awareness and producing drugs, screening devices and genetic tests.** It has also created an academic system that generates hundreds of thousands of articles about breast cancer and builds careers for thousands. Although there is no doubt individual researchers sincerely want to end breast cancer, every system is perfectly designed to achieve the results it gets.<sup>32</sup> The current system is perfectly designed to be lucrative, cautious and incremental.

Breast cancer research takes place within many disciplines, including laboratory science, clinical research, epidemiology, social sciences, and health services research. Generally, research organizations do strive for excellence and prioritize in order to make significant progress in their work. However, there are conflicting agendas that can hinder progress. Pursuit of fame and profit can take the emphasis away from achieving genuine advances for women. Emphasis on research for its own sake limits the avenues for application. Reluctance to include patient and advocate perspectives in research means that issues critical to those living with breast cancer and at risk are neglected, which results in less productive or useful research.

Breast cancer research over the decades has produced elegant science and thousands of important research papers, but little that has had a big impact on patients or those at risk. It is possible for researchers to gain significant acclaim for their work, and to be judged highly successful by the scientific world's measurement, without having helped a single patient. The system rewards safe ideas and

discourages innovative ones that might lead to the big breakthroughs in prevention and treatment. The infrastructure of breast cancer research is to keep things moving along as they have been and to reward people for doing safe, low-impact work. These obstacles are not scientific challenges but rather organizational and systematic dysfunctions. These are problems with solutions.

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**32** Coined by Paul Batalden, Director Health Care Improvement Leadership at Dartmouth College, the phrase "every system is perfectly designed to achieve exactly the results it achieves," has become the mantra of health care quality improvement leader Don Berwick, who is currently head of the Centers for Medicare and Medicaid (CMS).

## 5. We now have the tools, information, resources and wisdom to create a global strategy to end breast cancer; setting a deadline is the essential first step to starting a revolution in breast cancer.

Much has changed since 1971. Our understanding of the biology, etiology and genetics of breast cancer has increased dramatically. New disciplines have shed light on the process of innovation and how organizational systems evolve. And of course our capacity to gather, synthesize and analyze information is beyond anything even conceivable 40 years ago.

These developments create opportunities to conduct breast cancer research differently. By leveraging all available resources in a collaborative and rapid research process, it will be possible to cultivate the development of innovative ideas that will ultimately end breast cancer. The goal is not to create better tools to identify breast cancer, or better mechanisms for managing it. **The goal is to take what is already known and build upon that knowledge for the sole purpose of ending the disease.**

Other radical efforts have solved seemingly intractable problems; these successes shed light on how to accomplish the “impossible.” Perhaps the best-known example is the Apollo Project, which aimed to put a man on the moon. Historians have identified a few key components that shaped this bold and ultimately successful effort: **a sense of urgency, a commitment of resources, a multi-faceted management with a singular focus, and the accountability of a very clear and public deadline.**<sup>33</sup>

In the case of the Apollo Project, the potential for the Soviet Union to surpass the United States in terms of space technology and control of outer space created a strong sense of urgency. The (federal) funding was stable and more than adequate. But equally important was the Project’s focus, and ability to successfully manage and organize such a large and multi-faceted group of contributors.

Because so many different groups and individuals were involved, the potential for competition and disagreement was severe, and as a result the program had to be managed in a way that ensured all arms of the project were working toward the same ultimate goal, and were working together, rather than against one another. The project was also conducted in a way that helped make the time constraint more manageable. Many smaller projects were created within the larger project, and these small achievements along the way provided a sense of success and movement toward the ultimate goal and also provided a great deal of data and research along the way that was extremely significant for the project’s ultimate success.

Last but by no means least, the Apollo Project had a firm and unapologetic deadline. President Kennedy used the deadline to maintain the vision and create accountability. The world was watching.

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**33** “The Manhattan Project, the Apollo Program, and Federal Energy Technology R%D Programs: A Comparative Analysis” by Deborah D. Stine from the Congressional Research Service, “Project Apollo: A Retrospective Analysis” located at <http://history.nasa.gov/Apollomon/Apollo.html>, “Issues in NASA Program and Project Management,” edited by Dr. Edward J. Hoffman and located at [http://ntrs.nasa.gov/archive/nasa/casi.ntrs.nasa.gov/19950018145\\_1995118145.pdf](http://ntrs.nasa.gov/archive/nasa/casi.ntrs.nasa.gov/19950018145_1995118145.pdf)

## 6. NBCC is prepared to achieve the impossible.

**NBCC has a long history of taking on big issues in breast cancer, challenging business as usual, facing controversy head on and achieving success. Indeed, in many ways the entire history of NBCC has been about doing the impossible.**

It started with a small group of women who came together in 1991 to figure out how to go beyond awareness and mammography to actually *end the disease*. At the time there was no advocacy arm of the movement, and no organization interested in taking on this controversial and challenging role. To be effective, these women knew that they needed to pull together diverse interests and perspectives from all kinds of organizations concerned about breast cancer. A national coalition was needed, a coalition that focused exclusively on action and advocacy to end breast cancer. From this, NBCC was born.

There were many skeptics at the time. Political coalitions are notoriously ephemeral; how could so many competing interests ever stay united? Twenty years later, NBCC continues to thrive, defying the conventional wisdom about the fragility of coalitions. Again and again, NBCC has identified challenges, conducted thorough research, collaborated with creative thinkers in a wide range of disciplines, and then developed innovative solutions. Invariably that solution is then dismissed by others, even ridiculed, and deemed impossible. And then we do it anyway.

For example, in 1991 NBCC saw that breast cancer research was underfunded. But NBCC did not simply advocate for “more money.” We researched how much was actually needed, how much the research community could reasonably absorb. We determined that number to be \$300 million. We were told that it would be impossible to bring about that kind of increase. Then we did just that.

NBCC knew that money alone would not bring an end to breast cancer. We also knew that breast cancer advocates bring a unique and powerful perspective that was missing in the research process. This concept -- advocate involvement in the peer-review, priority setting and scientific research process-- was truly shocking to many in the research community. But we were not daunted, and went on to conceive and spearhead an unprecedented model of consumer involvement and innovative research in the DOD BCRP.<sup>34</sup>

NBCC determined it was not enough to have advocates at the table. We needed advocates who were educated and trained, comfortable with the language and concepts of science. Many doubted it was even possible to train advocates in such an in-depth way. We ignored these naysayers as well and went on to create Project LEAD<sup>®</sup>, NBCC’s premier science training course for activists. Now in its 16th year, the program has created a revolution in the world of breast cancer research and public policy. Project LEAD<sup>®</sup> graduates engage in a wide range of local and national forums where breast cancer decisions are made.

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**34** A number of articles have been written about the program’s consumer involvement. See Quantitative impact of including consumers in the scientific review of breast cancer research proposals. Andejaski Y, Bisceglia IT, Dickersin K, Johnson JE, Robinson SI, Smith HS, Visco FM, Rich IM. J Women’s Health Gen Based Med. 2002 May; 11(4): 379-88.PMID: 12150500 and Perspective from the Department of Defense Breast Cancer Research Program. Rich IM, Andejaski Y, Alciati MH, Crawford Bisceglia I, Breslau ES, McCall L, Valadez A. Breast Dis. 1998 Dec 10(5-6): 33-45.PMID: 15687584.

Clinical trials are essential to finding a way to end breast cancer. But NBCC saw that we didn't just need *more* clinical trials, but *better* trials. So we launched our Clinical Trials Initiative to make certain that the right research gets done correctly and quickly; that trained breast cancer survivors are included in trial design and accrual; and that policies encourage access to trials.

There was certainly no outpouring of support for this model, but we forged ahead, and in 1996, partnered with investigators and the biotechnology company to design and implement a Phase III clinical trial of a targeted therapy. In this groundbreaking collaboration, advocates, scientists and industry worked together to answer an innovative question in breast cancer.

No one thought this was reasonable or even possible before we did it.

This is true for NBCC's fight for access to quality health care as well. An NBCC advocate saw the pain and injustice of women in a federal health program receiving a diagnosis of breast cancer but no treatment, so we created a strategy for solving that problem. We were told that expanding a federal program to include treatment would be impossible. Indeed, it had never been done. But after many years of relentless NBCC grassroots advocacy, the Breast and Cervical Cancer Treatment Act<sup>35</sup> was finally enacted. It provides enhanced matching Medicaid funds to states so low-income women diagnosed with breast or cervical cancer through the federal screening program get coverage for treatment, and not just screening. It turns out it was possible.

## 7. NBCC is ready to spearhead a strategic, innovative, and integrative approach to ending breast cancer.

NBCC is now calling for a global strategy to end breast cancer. We have a plan to develop a specific blueprint to get there. We have a wealth of expertise in bringing together diverse groups of visionaries to break through the confinements of the current systems, and to envision new models that will profoundly impact our understanding of this disease. **We have a unique commitment to rigorous science-based advocacy that has generated great respect in the scientific and health care community.** That community is well aware of NBCC's steadfast commitment to evidence-based breast cancer policy, even when those policies are unpopular.

For more than a decade, NBCC has hosted "Blue Sky" or "Catalyst" meetings, bringing together truly unique combinations of expert perspectives, including advocates, policy makers, physicists, geneticists, health care providers, economists, philosophers, mathematicians, epidemiologists and others. These gatherings have generated invaluable strategic guidance for NBCC, and have brought the organization to the point where it is ready to spearhead this global effort.

NBCC is now expanding its catalyst meetings to address important questions in breast cancer and develop collaborations to design and implement strategies to answer them. Catalyst meetings will

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**35** After four years of an intense grassroots lobbying campaign by the NBCC nationwide network, on October 24, 2000, the Breast and Cervical Cancer Treatment Act (P.L. 106-354) was signed into law. [http://www.stopbreastcancer.org/index.php?option=com\\_content&task=view&id=615&Itemid=103](http://www.stopbreastcancer.org/index.php?option=com_content&task=view&id=615&Itemid=103)

be held around more focused issues that are often overlooked but could have a dramatic impact on ending breast cancer. As our first project in the campaign we are currently working with a diverse group of stakeholders to create a five-year strategic plan to catalyze the development of a preventive breast cancer vaccine that could revolutionize breast cancer prevention.

Spurring innovation is just one component of this effort. No discovery or innovation about breast cancer treatment or prevention has any value unless it *actually helps* people at risk of, or diagnosed with, breast cancer. We will continue our mission to ensure the health care system is accountable to the users and the public. And a major component of the 2020 Deadline will be annual reports on progress toward achieving the mission, in order to hold everyone, including ourselves, accountable.

What is true for research and health care is also true for advocacy: more of the same will not produce different results. **By calling for an end to breast cancer by 2020, NBCC is calling for the end of business as usual. We have no desire to increase awareness of breast cancer, or to continually increase funding for research. Indeed, our foremost goal is to bring about the demise of the organization by accomplishing its mission.**

## Conclusion

The 2020 Deadline is not about NBCC, It is a call to all of us who care about breast cancer to push toward the goal. We are calling for a global campaign to end breast cancer by 2020. This bold and radical goal is rooted in the sense of urgency, tenacity, and focus that is the hallmark of everything we do. We are uniquely positioned for such action given our history of challenging and changing science, public policy, advocacy and health care. It is time, once again, for us to launch a revolution in how we think about breast cancer and how to eradicate the disease. Breast Cancer Deadline 2020. The end of breast cancer by 2020. It's time.