Breast Cancer Deadline 2020® 2nd Annual Progress Report

National Breast Cancer Coalition

The **Breast Cancer** Deadline

2020

Founded in 1991, the National Breast Cancer Coalition's (NBCC) mission is to eradicate breast cancer through the power of action and advocacy. On September 20, 2010, NBCC set a deadline and launched a plan of action to reach its mission: **Breast Cancer Deadline 2020**[®]—the end of breast cancer by January 1, 2020.

NBCC increases federal funding for breast cancer research; monitors how research funds are spent; expands access to quality health care for all; and ensures that trained advocates influence all decision making that affects breast cancer.

NBCC links hundreds of organizations and tens of thousands of individuals from across the country into a dynamic, diverse coalition that gives breast cancer a meaningful voice in Washington, DC and state capitals, in laboratories and health care institutions, and in local communities everywhere.

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National Breast Cancer Coalition

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EXECUTIVE SUMMARY

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INTRODUCTION

In 2010, the National Breast Cancer Coalition set a deadline to end breast cancer and launched a plan to achieve it. **Breast Cancer Deadline 2020**[®] is a call to action for all stakeholders to focus efforts on ending the disease by the end of the decade. As part of **Breast Cancer Deadline 2020**[®], NBCC issues <u>Annual Progress Reports</u>. The reports, summarizing the state of breast cancer as well as the status of NBCC's work to end breast cancer, hold NBCC and the entire breast cancer community accountable to **Breast Cancer Deadline 2020**[®]. <u>The 2011 Progress Report served as a baseline</u> and provided a snapshot of the current state of breast cancer. With a review of breast cancer trends, research, advocacy and public policy, the report portrayed the reality of breast cancer and the lack of adequate progress despite the significant public and private resources directed at the disease.

This 2nd Annual **Breast Cancer Deadline 2020**[®] Progress Report provides an update with the latest data on breast cancer incidence and mortality; information on public policy and advocacy; a look at the current research priorities as demonstrated by research funding; an analysis of the breast cancer conversation in the media during 2011 National Breast Cancer Awareness Month; and finally, an update on **Breast Cancer Deadline 2020**[®] activities.

This report must be read in conjunction with the Baseline Report issued in 2011. In the 2012 report, NBCC provides updates only where information has changed. It is important to note that there were no "breakthroughs" in treatment or diagnosis in the past year, and the information in the Baseline Report remains the most pertinent.

There are many myths and misunderstandings that surround breast cancer. In order to make real progress toward saving lives and ending breast cancer, we need to better understand its reality at all levels. The reality is troubling.

Breast cancer continues to take a toll in the US and globally despite significant attention and resources directed at the disease. Billions of dollars have been invested in breast cancer research, and many Breast cancer continues to take a toll in the US and globally despite significant attention and resources directed at the disease.

organizations and public health officials continue to focus attention on early detection and awareness campaigns as the primary approach to addressing breast cancer.

Given the attention and resources directed to breast cancer, the public understandably believes that we have made significant progress. As shown in the Baseline Report and in this year's Progress Report, that is not the case. We know little about how to prevent breast cancer or how to prevent deaths from the disease. While we have discovered new ways to treat breast cancer, they have not had a great effect on the important outcomes: preventing breast cancer and making certain no one dies of it.

BREAST CANCER STATISTICS: THE NUMBERS TELL A COMPELLING STORY

The trends for breast cancer incidence and mortality have not changed since NBCC issued its Baseline Report in 2011. The overall number of women being diagnosed continues to increase as the population ages, though the rate remains constant, and mortality continues to decline slightly.

Worldwide, breast cancer accounts for nearly a quarter of all cancers in women. In 2008, there were 1.4 million women diagnosed with the disease and 458,503 deaths.¹

In the United States, in 2012, it is estimated that more than 290,000 women and 2,190 men will be diagnosed with breast cancer. 39,510 women and 410 men will die of the disease.² That is one death every 14 minutes.

By any standard, we have not made adequate progress. Despite years of campaigns to raise awareness, ever expanding screening programs, increased fundraising efforts and more research, there has been little impact on the important outcomes in breast cancer. Breast cancer incidence and mortality have not changed significantly.

If we continue making progress at the current rate, it could take a few centuries to end breast cancer. These are not merely statistics, they represent millions of lives. These losses are unacceptable. In 2030, with no major changes in prevention or treatment, it is estimated that 747,802 women will die from breast cancer worldwide.³

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.⁴ US breast cancer mortality has been declining but only slightly. In 1991, in the United States, 119

women died of breast cancer every day.⁴ This year, that number is estimated to be 108. If we continue making progress at the current rate, it could take a few centuries to end breast cancer. These are not merely statistics, they represent millions of lives. These losses are unacceptable.

Incidence

Overall incidence of breast cancer has fluctuated over the years. Recently, researchers at the National Cancer Institute (NCI) projected that the overall breast cancer incidence rate will stay the same through 2016. The median age at diagnosis is 61.⁴ Because of increased screening beginning in 1980, there has been a dramatic increase in the incidence of ductal carcinoma in situ (DCIS), abnormal cells contained within the milk ducts that have not spread to other parts of the body. Most of DCIS will never become cancer. However, we are not able to distinguish between the harmful kind of DCIS (that will develop into cancer) and the harmless kind; as a result, many women are treated with interventions that will not help them and could hurt them.⁴

Mortality and Survival

Despite fluctuations in breast cancer incidence, and dramatic increases in the use of mammography, there has only been a slow, gradual decrease in the rate of breast cancer deaths, or breast cancer mortality, over

time. Women do not die of primary breast cancer. Over 90% of breast cancer deaths are due to the spread of the disease to other parts of the body. While we want to believe we have made significant progress in saving lives, that is not the case. The incidence of women diagnosed with advanced breast cancer has not changed. Rates of diagnosis of truly lethal disease have remained stable since 1975.³ Mortality rates have not changed significantly. Between 1975 and 1990, the mortality rate increased slightly then began decreasing slightly

While many mistakenly point to five-year survival statistics as proof of progress, an estimated 20% to 30% of women diagnosed with invasive breast cancer will have a recurrence of their disease and may go on to die of the disease, yet they are included as survivors in the fiveyear survival statistics. in the late 1990s for all women, with the highest rate of decrease in white women.³ Yet this year, 39,510 women and 410 men will die of breast cancer. While a slight decrease in mortality is an accomplishment, it is far from success.

Survival statistics do not reflect the real experience of people with breast cancer. The NCI reports that five-year breast cancer survival is 98% for localized disease. Survival rates are skewed by screening: the

more you screen, the more you find and thus more women will be alive at five years. But they were not going to die of breast cancer in that time frame even if they had not been screened.⁵ And these numbers do not take recurrence into account. While many mistakenly point to five-year survival statistics as proof of progress, an estimated 20% to 30% of women diagnosed with invasive breast cancer will have a recurrence of their disease and may go on to die of the disease, yet they are included as survivors in the five-year survival statistics. We still do not know how to prevent recurrence and metastasis or how many of the women reported to have survived five years will go on to have their breast cancer recur.

The Uncomfortable Reality Behind Early Detection

A great deal of attention and resources have focused on the area of early detection. A mantra that has been drummed into our consciousness over the past forty years is that early detection saves lives. The reality is otherwise. About 70% of women in this country over age 40 have had a mammogram in the last two years.⁶ Unfortunately, randomized controlled trials for mammography have shown, at best, a marginal benefit.^{7,8} Breast self-exam (BSE) has also long been a key women's health mantra. But research has demonstrated that routine BSE does not lead to a decrease in mortality from breast cancer nor does it find breast cancer at an earlier stage.^{9,10}

Yet many resources are devoted to giving the message of early detection and promoting breast self-exam and mammography screening for younger and younger populations. Attempts to apply evidence to the message of early detection are often met with anger and derision, as evidenced by the response to the revised screening guidelines issued by the United States Preventive Services Task Force in 2009. But these are matters of science. As our knowledge progresses, our beliefs must change to accommodate new information, no matter how much this challenges long-held beliefs and no matter how much we do not like the answer.

WE HAVE MADE SOME PROGRESS IN THE TREATMENT OF BREAST CANCER

We have made some progress in breast cancer treatments. We have learned that not all breast cancers are the same. We now divide breast cancer into subtypes, based on the biology of the tumor. We have made some progress toward developing treatments targeted to different subtypes. But the majority of women with breast cancer still receive the same treatment as though all breast cancers were the same. In reality, to date, our knowledge of the biology of breast cancer has not been translated into many new therapies to treat it.

There have been no major advances in treatment for breast cancer in the last year. For decades, breast cancer treatment has included surgery, radiation therapy, chemotherapy, and/or hormonal therapy, and within the past 15 years, targeted therapy. Ironically, much of the recent progress in treatment has been in doing less. In the 1970s, the primary treatment for breast cancer was a radical mastectomy, but once researchers found no difference with respect to outcomes in patients with lumpectomy versus patients with total mastectomy, the standard of care shifted to a less invasive surgery. Studies have shown that removing a few lymph nodes has the same survival advantage as removing most if not all.¹¹ These two developments have a major impact on quality of life. While important, they do not change the mortality statistics.

Meanwhile, the cost of treating breast cancer continues to rise without accompanying significant decreases in breast cancer mortality. The national cost of cancer care in 2010 was estimated to be \$124.6 billion, with female breast cancer care leading all cancer sites at an estimated \$16.5 billion.¹² Despite that investment, a person with a new diagnosis of cancer has approximately a one in five chance of failing to receive elements of cancer care that are evidence-based and consistent with practice standards.¹³ And millions of Americans have no insurance, which not surprisingly has an impact on the quality of their health care.

Like all medical treatments, breast cancer treatments can be harmful as well as helpful. Common morbidities include cardiac complications and lymphedema, among others. And the treatments can themselves be life-threatening. We need treatments that prolong life or significantly increase quality of life, with minimal risk. Too often progress is defined by new treatments that do neither.

PUBLIC POLICY PLAYS A SIGNIFICANT ROLE IN ALL ASPECTS OF BREAST CANCER

Breast cancer is a political issue. The level of government funding for research, the expansion and regulation of access to health care, the regulatory process for drug approval, and health insurance are just some of the issues that are determined through the political process.

From 1991 to 2012, over 870 resolutions and bills with the words "breast cancer" were introduced in the United States Congress. Many more have been introduced in state legislatures. On the federal level, of the hundreds introduced since 1991, 11 resolutions were agreed to and 44 bills became law.¹⁴

As of July 2012, the 112th Congress had introduced a total of over 9,500 pieces of legislation, including the <u>Accelerating the End of Breast Cancer Act</u> (S. 3237/H.R. 3067), a bill created by NBCC to support the goals and efforts of **Breast Cancer Deadline 2020**[®]. Yet only 150 have become law.¹⁵ The only bill passed in this Congress that directly influences public health issues was H.R. 2005, the *Combating Autism Reauthorization Act*, which was passed in May of 2011.

BREAST CANCER RESEARCH MAY BE WELL FUNDED, BUT ARE THE FUNDS WELL SPENT?

As outlined in the 2011 Baseline Report, billions in public funding, private investment and charitable contributions have been directed toward decreasing the burden of breast cancer over the last several decades, but the investment has not paid off in dramatic improvements in incidence or mortality from the disease.

....billions in public funding, private investment and charitable contributions have been directed toward decreasing the burden of breast cancer over the last several decades, but the investment has not paid off in dramatic improvements in incidence or mortality from the disease. The US Government remains the largest funder of breast cancer research in the US; although the NCI invests the most resources, а variety of other agencies are also involved. In 2010, the most recent year with complete data, the National Cancer Institute directed \$631,228,554 to breast cancer research. Approximately half of that research was directed at areas relevant to women

after the disease has appeared—early detection, treatment of primary and metastatic breast cancer, survivorship, and outcomes research. Sixteen percent of the funding was directed at looking at the causes of breast cancer, nine percent at prevention, and approximately one-fifth of the funding was directed at understanding the biology of the disease.¹⁶

The federal government also funds research through the Department of Defense Breast Cancer Research Program (DOD BCRP). In 2010, the DOD BCRP funded research grants totaling \$138,140,762. One-fourth of the 2010 DOD BCRP grants were awarded for treatment research, and approximately one-half were for research on the biology of the disease, which included research on progression and metastasis (25%) and on initiation of disease (24%). Another 8% of overall funds was directed at research on the causes or etiology of breast cancer and 2% toward prevention research.¹⁷

Private philanthropy underwrites a significant amount of research in breast cancer. The largest private funder of breast cancer research is Susan G. Komen for the Cure, which awarded \$57 million in grants in 2011.¹⁸ Additional funders exist across the country, from gifts in the hundreds of millions of dollars to local walks that raise a few thousand. With a diversity of supporters and vast number of donations and events, it is not possible to determine the amount of funding in this category.

ClinicalTrials.gov collects information about federally and privately supported research once it reaches the clinical stage. On March 26, 2012, there were 123,184 clinical trials listed; 4,281 were listed as breast cancer trials and 35% (1,538) of these were listed as trials for metastatic breast cancer.

BREAST CANCER ADVOCACY HAS MADE A DIFFERENCE

There are probably thousands of breast cancer groups in this country alone and a growing global movement.

Breast cancer advocates can help shape the breast cancer research agenda, the federal drug approval process, health care system, and federal and state legislation. They can serve as liaisons between patients and physicians, as well as patients and the scientific community. Some groups provide direct services such as hotlines, support groups, counseling, educational materials, financial aid, and community presentations.

During the past year, women's health issues, including breast cancer, were embroiled in controversy. The nature and extent of the fallout, both on political support for women's health issues, and on fundraising around breast cancer and other women's issues, remains to be seen.

THE PORTRAYAL OF BREAST CANCER BY THE MEDIA DOES NOT FULLY REFLECT THE REALITIES OF THE DISEASE

The **Breast Cancer Deadline 2020**[®] Baseline Report did not address media coverage of breast cancer issues. This year's report includes an analysis of breast cancer coverage during 2011 National Breast Cancer Awareness

Month (NBCAM), because understanding the current conversation around breast cancer issues will be important in shifting the status quo and achieving greater progress.

Prevention/risk factors was the most common theme across all articles, followed closely by screening and then treatment. Two-thirds of articles that went into detail on screening mammography presented a balanced view of screening with its limitations. This shows that the harms of mammography, including radiation, unnecessary biopsies, anxiety and overdiagnosis, Often times, a picture was painted of survivors who are disease-free and overcame the disease. Only about 1 in 9 articles portrayed women battling metastatic disease.

are being shared with the general public. In addition, one out of five articles accurately reported that not all breast cancers are the same, portraying the complexity of the disease.

More than half of the articles included one or more personal stories. Among 24 personal stories that shared the age at diagnosis, merely three of the women were over 60 years of age at diagnosis. This does not reflect reality: 50% of breast cancer occurs in women aged 62 and older. It comes as no surprise that young women who read these 'news' reports throughout the month believe they have a much higher risk of the disease than they actually do.^{19,20}

Furthermore, the majority of personal accounts were primary, early stage, breast cancer diagnoses. Often times, a picture was painted of survivors who are disease-free and overcame the disease. Only about 1 in 9 articles portrayed women battling metastatic disease.

Keys to ending the disease—understanding primary prevention and how to prevent metastasis—do not receive significant coverage. While progress is being made, changing the conversation in the media remains a challenge. Continuing to push for accurate coverage of breast cancer in the media and attention to the areas that will lead to eradication of the disease is a priority for **Breast Cancer Deadline 2020**[®].

THE BREAST CANCER DEADLINE 2020° STRATEGY

It is clear that "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 health care 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.

During the past year, NBCC began to implement a strategic plan of action for **Breast Cancer Deadline 2020**[®] in four key areas.

Research, Including New Strategies and Collaborations

The core of the **Breast Cancer Deadline 2020**[®] campaign is a research approach to identify the important questions in breast cancer and develop strategies to discover the answers to those questions. In order to identify the questions and start building the strategies, NBCC held two strategic summits in 2011 around the priority areas of primary breast cancer prevention and the causes and prevention of breast cancer metastasis.

Through the Artemis Project[®], NBCC has created an innovative, advocateled, mission-driven model, which ensures appropriate focus on the end result. A diverse, multi-disciplinary group of stakeholders was convened to consider, discuss and prioritize issues related to each topic. NBCC will then select specific issues and build collaborations around those issues as part of the Artemis Project[®].

Through the Artemis Project[®], NBCC has created an innovative, advocateled, mission-driven model, which ensures appropriate focus on the end

result. The participants in these project collaborations will design and implement research plans, and NBCC will award seed grants to begin the necessary work.

The first project to arise from this work brings together a collaborative group of advocates, scientists and other stakeholders to take a strategic, systematic, yet broad approach to the design of a five-year development plan for a <u>breast cancer preventive vaccine</u>. In March 2012, NBCC held the <u>second annual meeting</u> for the project. A request for proposals for the first seed grant was also issued at that time with a grant distribution scheduled for the summer, followed by a second call for proposals for another research topic within the project.

A Public Policy Approach, Including Federal Legislation and a Plan to Ensure Worldwide Access to Lifesaving Interventions

Breast Cancer Deadline 2020[®] work in public policy during the past year included educating Congress and the Administration on strategies to end breast cancer by 2020.

Based on NBCC's public policy work over the past years and the feedback gleaned during a January 2011 Public Policy Roundtable, NBCC developed the first piece of legislation to support and complement the work of **Breast Cancer Deadline 2020**[®]. In September 2011, the <u>Accelerating the End of Breast Cancer Act</u> was introduced in the US House of Representatives. Companion legislation was introduced in the Senate in May 2012.

NBCC is gathering signatures on a <u>petition to the President</u> calling on him to commit to **Breast Cancer Deadline 2020**[®]. The petition signatures will be delivered to the President shortly after Inauguration Day— January 21, 2013.

Grassroots Advocacy and Education of a Large Corps of Activists Around the Globe to Engage Their Communities

The Center for NBCC Advocacy Training plays a key role in training breast cancer advocates to work in their communities and side-byside with scientists to change the conversation in breast cancer, set Many more advocates were mobilized in support of the campaign through online education, grassroots outreach, and the continued development of local networks, both here in the US and in other countries around the world.

research priorities, and design and focus research on key areas that will end the disease by 2020. The Center conducted training events in several locations in the US and also enhanced its online offerings to share beginner and advanced education programs to advocates across the globe.

The 2011 NBCC Annual Advocacy Training Conference focused on **Breast Cancer Deadline 2020**[®] in order to engage nearly 1,000 attendees in the work of the campaign. Many more advocates were mobilized in support of the campaign through online education, grassroots outreach, and the continued development of local networks, both here in the US and in other countries around the world.

Communications and Media Outreach to Change the Conversation to Ending Breast Cancer by 2020

NBCC launched an expansive effort to change the conversation around breast cancer to a dialogue about ending the disease by 2020. NBCC convened and communicated with journalists, editors and others who work in the media to educate them about breast cancer and build their understanding of the realities of the disease and the current barriers to progress. At the same time, NBCC also shared the plans, activities and goals of **Breast Cancer Deadline 2020**[®] directly with the public and key stakeholder groups through presentations at scientific meetings, the web, social media and print materials.

CONCLUSION

Over the course of the last several decades, the investment in breast cancer has not led to significant progress in ending the disease or in preventing deaths from the disease. This did not change in the past year since the publication of the <u>Baseline Report</u>. This is true for research and health care and also advocacy.

Since 1971 when the war on cancer was launched, our understanding of the biology, etiology and genetics of breast cancer has increased. 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. NBCC launched **Breast Cancer Deadline 2020**° to leverage these past investments and innovations in order to catalyze real progress in breast cancer.

In the first full year of the **Breast Cancer Deadline 2020**[®] campaign, NBCC moved quickly to put its plan into action. We have mobilized In the first full year of the **Breast Cancer Deadline 2020**[®] campaign, NBCC moved quickly to put its plan into action.

a collaborative of renowned experts in epidemiology, immunology, clinical care, biotechnology, product development and advocacy to begin work on two key areas: preventing the disease from ever developing; and preventing metastasis, the spread of the disease to other organs, which causes 90% of breast cancer deaths. We have introduced bipartisan legislation to support our efforts in the US Congress while also building support among public officials. We have educated and mobilized grassroots advocates and organizations to spread the word about **Breast Cancer Deadline 2020**° and engage women and men in the campaign. And, we have reached out to the media and shared information with the general public in order to change the conversation in breast cancer to one that is focused on ending the disease and saving lives. With less than eight years remaining until January 1, 2020, it is critical that we continue to put forth our most ambitious efforts and pursue them with uncompromised commitment. The goal is achievable with the right amount of passion, leadership and funding. It will require all of us who care to play a role in meeting the goal to find the will, the strength, and the belief to do what it takes to achieve the end of breast cancer. The tools, information, resources and wisdom exist to create a global strategy to end breast cancer.

1 INTRODUCTION

1 | INTRODUCTION

In 2010, the National Breast Cancer Coalition set a deadline to end breast cancer: January 1, 2020—Breast Cancer Deadline 2020[®]. As part of Breast Cancer Deadline 2020[®], NBCC issues <u>Annual Progress Reports</u>. The reports, summarizing the state of breast cancer as well as the status of NBCC's work to end breast cancer, hold NBCC and the entire breast cancer community accountable to Breast Cancer Deadline 2020[®]. The 2011

It is important to note that there were no "breakthroughs" in treatment, or diagnosis, in 2011 and the information in the Baseline Report remains the most pertinent. Progress Report served as a baseline, giving an overview of breast cancer trends, including a discussion of the research landscape, advocacy, and public policy. The report portrayed the reality of breast cancer and the lack of adequate progress despite the significant public and private resources directed at the disease. The report also offered the advocate perspective on barriers that have hindered progress.

This report will provide an update with the latest data on breast cancer incidence and mortality; information on public policy and advocacy; a look at the current research priorities as demonstrated by research funding; an analysis of the breast cancer conversation in the media during 2011 National Breast Cancer Awareness Month; and finally, an update on **Breast Cancer Deadline 2020**[®] activities.

This second annual Breast Cancer Deadline 2020[®] Progress Report must be read in conjunction with the Baseline Report issued in 2011. In this 2012 report, NBCC provides updates only where information has changed. For example, NBCC does not again review the overall landscape of breast cancer treatment, but reports on a few studies that were released over the past year. It is important to note that there were no "breakthroughs" in treatment, or diagnosis, in 2011 and the information in the Baseline Report remains the most pertinent.

2 | BREAST CANCER STATISTICS

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2 | BREAST CANCER STATISTICS

The trends for breast cancer incidence and mortality have not changed since NBCC issued its Baseline Report in 2011. (See trends for incidence and mortality in Figures 1, 2 and 3, updated with the latest SEER data.) The overall number of women being diagnosed continues to increase as the population ages, though the rate remains constant, and mortality continues to decline slightly. The National Cancer Institute

(NCI) estimated that in the United States more than 288,000 women and 2,140 men developed invasive and in situ breast cancer in 2011, and 39,520 women and 450 men died from the disease.¹ An even larger number are expected to develop the disease during 2012—with over 290,000 women and 2,190 men predicted to receive a diagnosis. Breast cancer will take the lives of approximately 39,510 women and 410 men in the US this year alone.²

The trends for breast cancer incidence and mortality have not changed since NBCC issued its Baseline Report in 2011.

Global statistics are not updated as

frequently. As reported last year, breast cancer accounts for nearly a quarter of all cancers in women worldwide. In 2008, there were 1.4 million women diagnosed with the disease and 458,503 deaths.³ In 2015, an estimated 1.6 million women will be diagnosed with breast cancer around the world.⁴



Figure 1. Female Breast Cancer Incidence Rates* by Race and Ethnicity, US, 1975-2008

*Rates are age-adjusted to the 2000 US standard population

Data source: Surveillance, Epidemiology, and End Results (SEER) Program, 1975-2008, Division of Cancer Control and Population Science, National Cancer Institute, 2012. Data for whites and blacks are from the SEER 9 registries. Data for other race/ethnicities are from the SEER13 registries. Hispanics and Non-Hispanics are not mutually exclusive from whites, blacks, Asian/Pacific Islanders, and American Indians/Alaska Natives.



Figure 2. Female Breast Cancer Incidence Rates* by Stage**, US, 1975-2008

* Rates are age-adjusted to the 2000 US standard population.

**Localized - confined to primary site in breast; regional - spread to regional lymph nodes; distant - cancer has metastasized

Data source: Surveillance, Epidemiology, and End Results (SEER) Program SEER*Stat Database: Incidence - SEER 9 Regs Research Data, Nov 2010 Sub (1973-2008) <Katrina/Rita Population Adjustment> - Linked To County Attributes - Total U.S., 1969-2009 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2011 (updated 10/28/2011), based on the November 2010 submission.





*Rates are age-adjusted to the 2000 US standard population

Data source: US Mortality Files, National Center for Health Statistics, CDC. Rates for American Indian/Alaska Native are based on the CHSDA (Contract Health Service Delivery Area) counties.

It is important to look at incidence of both in situ and invasive breast cancer. Non-invasive in situ carcinoma is a condition where abnormal cells are found within the milk ducts or lobules and have not spread to the surrounding tissues in the breast or other parts of the body.⁶

In the United States in 2011, 230,480 women were diagnosed with invasive breast cancer and an estimated 57,650 women were diagnosed with non-invasive in situ carcinoma.¹ Of these cases, about 85% were ductal carcinoma in situ (DCIS), meaning the abnormal cells were contained within the milk ducts, and approximately 15% were lobular carcinoma in situ. The terms are misleading however, as these lesions are not cancer. Incidence rates of in situ carcinoma increased rapidly during the 1980s and 1990s with widespread use of mammography screening, and this increase was the largest in women aged 50 and older.⁵ The incidence of DCIS increased over seven-fold from 1980 to 2007, from 4.8 per 100,000 to 34.6 per 100,000. Since 2004, incidence rates of in situ breast cancer have been stable in white women and increasing in black women by 2.0% per year.² Today, approximately one woman is diagnosed with DCIS for every four women diagnosed with invasive breast cancer.⁶

Despite fluctuations in breast cancer incidence, and dramatic increases in the use of mammography, there has only been a slow, gradual decrease in the rate of breast cancer deaths, or breast cancer mortality, over time. Recently, researchers at the NCI projected that the overall breast cancer incidence rate will stay the same through 2016. However, the rates of ERpositive breast cancers will increase 5.3% while the rates of ER-negative breast cancers will decrease by 11.4% from 2009 to 2016.⁷

Despite fluctuations in breast cancer incidence, and dramatic increases in the use of mammography, there has only been a slow, gradual decrease in the rate of breast cancer deaths, or breast cancer mortality, over time. Between 1975 and 1990, the mortality rate increased by 0.4% annually, but began decreasing in 1990, with an average decrease of 2.2% annually from 1990 to 2008.⁵

While many mistakenly point to five-year survival statistics as proof of progress, an estimated 20% to

^{30%} of women diagnosed with invasive breast cancer will have a recurrence of their disease⁸ and may go on to die of the disease, but are included as survivors in the five-year survival statistics. We still do not know how to prevent recurrence and metastasis or how many of the women reported to have survived five years will go on to have their breast cancer recur.

3 | BREAST CANCER TREATMENT

		2014

2011

3 | BREAST CANCER TREATMENT

Over the years, we have increased our understanding of breast cancer, and there has been an improvement in slowing or halting disease progression for some women. <u>However, as described in the Baseline Report,</u> <u>surgery, chemotherapy, hormonal therapy, radiation, and targeted therapy have remained the standard of</u> <u>care for breast cancer for several decades.</u> That did not change in 2011. Year after year, time and money are devoted to testing the newest drug which may minimally improve progression-free survival, but has no effect on overall survival. It is important to note that the term "progression-free survival (PFS)" does not mean a woman survives longer than she would have without the drug. The term refers to the length of time during and after treatment in which a patient is living with a disease that does not get worse. PFS is measured using imaging technology. When PFS is reported as an outcome without any corresponding data on improved quality of life, the study has not demonstrated actual clinical benefit for the patients.</u>

One sign of progress over 2011 is that there appears to be a growing recognition that more treatment is not necessarily better treatment.

However, there have been no major advances in treatment for breast cancer in the last year.

3.1 HORMONAL THERAPY

Although patients with hormone receptor positive disease can turn to endocrine therapy, their bodies may eventually (or initially) become resistant to the treatment. Aromatase inhibitorssurgery, chemotherapy, hormonal therapy, radiation, and targeted therapy have remained the standard of care for breast cancer for several decades.

(Als), hormonal therapy for estrogen receptor (ER) positive breast cancers, work through a mechanism that reduces the amount of estrogen in the body. However, just as with targeted therapies and many other cancer drugs, not all patients respond to the therapy (de novo resistance) and others who do, often acquire resistance later. This past year, a study announced that the combination of everolimus (Afinitor), a targeted therapy, and the aromatase inhibitor exemestane (Aromasin), improved progression-free survival by four months in women diagnosed with metastatic breast cancer, according to results of the Breast Cancer Trials of Oral Everolimus (BOLERO-2).¹ The study does not provide information on overall survival.

3.2 TARGETED BREAST CANCER TREATMENT

After promising Phase II results suggesting that BSI-201(iniparib), a poly (ADP-ribose) polymerase (PARP) inhibitor extended survival by an average of almost five months over chemotherapy alone in triple negative cancers,² many had hope that PARP inhibitors would be the major advance in treatment this past year. Unfortunately, early in 2011, BiPar Sciences announced disappointing results from their randomized Phase III trial evaluating the PARP inhibitor, BSI-201 (iniparib), in patients with metastatic triple negative breast cancer.³ The Phase III results found no improvement in overall or progression-free survival in first line treatment.³

While trastuzumab (Herceptin) is considered a success story as targeted breast cancer therapy, about half of HER-2 positive patients do not respond to trastuzumab therapies due to various resistance mechanisms,⁴ and those who do often build up resistance within a year or two.^{5,6} In the CLEOPATRA trial,⁷ researchers explored adding pertuzumab (Perjeta), another kind of targeted therapy, to trastuzumab and

chemotherapy in patients who eventually stop responding to the targeted therapy. The median progression-free survival was prolonged by 6.1 months, from 12.4 months in the control group to 18.5 months in the pertuzumab group.⁷

3.3 DRUG DEVELOPMENT, EVALUATION, AND APPROVAL

For women living with metastatic breast cancer, the Food and Drug Administration's (FDA) decision to withdraw approval of bevacizumab (Avastin), was probably the most impactful event of 2011. In November For women living with metastatic breast cancer, the Food and Drug Administration's (FDA) decision to withdraw approval of bevacizumab (Avastin), was probably the most impactful event of 2011.

2011, FDA Commissioner Margaret Hamburg, MD announced her decision to revoke the agency's approval of the breast cancer indication for bevacizumab.⁸ According to Dr. Hamburg, "After reviewing the available studies, it is clear that women who take Avastin for metastatic breast cancer risk potentially life-threatening side effects without proof that the use of Avastin will provide a benefit, in terms of delay in tumor growth, that would justify those risks. Nor is there evidence that use of Avastin will either help them live longer or improve their quality of life." ⁸

3.4 MORBIDITY AND MORTALITY CAUSED BY TREATMENTS

Breast cancer treatments do carry risks of morbidity and mortality as made clear in the Baseline Report and in at least one study reported over the past year. Aromatase inhibitors (Als), a class of endocrine therapy drugs used to treat postmenopausal breast cancer patients, are associated with a reduction in breast cancer recurrence but not in improved overall survival. One systematic review conducted during the year indicated that a possible reason might be that the cumulative toxicity of Als when used as up-front treatment is greater than that of tamoxifen, possibly increasing the risk of death from non-breast-cancer causes. The review also indicated that Als given for two to three years after initial tamoxifen treatment were associated with a lower risk of death from other causes compared to the use of Als or tamoxifen alone for five years. ⁹

Other research findings during the year gave support for removing anthracyclines from some treatment protocols. Researchers evaluated the efficacy and safety of a nonanthracycline regimen with trastuzumab, in breast cancer that overexpresses HER-2. The benefits were similar in progression-free and overall survival without adding anthracyclines to trastuzumab, thereby avoiding the risk of additional cardiac toxicity from anthracyclines. Thus the risk benefit ratio favored the nonanthracycline regimen given its similar efficacy, and fewer toxic effects.¹⁰

Also in 2011, research suggested that only a small subset of breast cancer patients benefit from anthracycline chemotherapy, and that those patients could derive equal benefit from a less toxic, targeted, but more expensive, treatment.¹¹ In a study of almost 5,000 tumors from women with metastatic breast cancer, investigators found that amplification (extra copies) of the topoisomerase II-alpha (TOP2A) gene in the tumors predicted response to anthracycline chemotherapy. However, women with over expression of TOP2A who were treated with trastuzumab and no anthracycline did just as well. Since approximately 35% of HER-2-positive tumors also have over expression of TOP2A, and no TOP2A amplification was found in HER-2-normal tumors, this may be a clinically useful predictor for response to anthracycline-based chemotherapy. ¹¹

3.5 QUALITY CARE

As explained in the 2011 Baseline Report, there are few good measures of quality of care in breast cancer.

One aspect of quality is whether the care received is based on established, recognized and evidence-based guidelines. There are several published guidelines for breast cancer treatment, few of which are based on high levels of evidence. Major issues remain in quality in breast cancer care, especially in the areas of access, overdiagnosis and overtreatment. No major changes occurred in these areas since publication of the 2011 Baseline Report.

Over the past year, there has been some development in the area of patient engagement that may ultimately have a favorable impact on the general quality of health care delivery nationally and as such would improve breast cancer care delivery as well.

The *Patient Protection and Affordable Care Act* of 2010 established the Patient-Centered Outcomes Research Institute (PCORI)¹² as an independent, not-for-profit entity. PCORI's mission is to help people make informed health care decisions and improve health care delivery by producing high integrity, evidence-based information that derives from research guided by patients, caregivers and the broader health care community.

The statutory language supports a strong patient-centered orientation in terms of participation on the Board of Governors and standing committees, in the grants review process, and in integrating public comment. During its first year, PCORI defined "Patient-Centered Research" through a public comments process, and identified the following four patient-centered research questions that will guide its work:¹³

- "Given my personal characteristics, conditions and preferences, what should I expect will happen to me?"
- "What are my options and what are the potential benefits and harms of those options?"
- "What can I do to improve the outcomes that are most important to me?"
- "How can clinicians and the care delivery systems they work in help me make the best decisions about my health and health care?"

Another related patient engagement area of quality care work which has gained recognition this year is the area of Shared Decision Making (SDM). Pioneered in 1999 by the Dartmouth Center for Informed Decision Making, the first such center in the country, SDM is the collaboration between patients and caregivers to come to an agreement about a health care decision, based on medical evidence and patient values and preferences. In June 2012, the Center for Medicare and Medicaid Innovation (CMMI) awarded the Dartmouth Institute for Health Policy and Clinical Practice and the Dartmouth-Hitchcock health system a three-year, \$26 million Innovation Grant to implement Shared Decision Making for patients across their 15 health system member network, impacting a patient population of 50 million across 17 states. The project is predicted to save \$64 million over 3 years, largely due to reduced utilization and costs that have been shown to occur when patients are engaged and empowered to make health care decisions based on their own values and preferences. Evidence is still at the core of Shared Decision Making and should inform both clinicians and patients when weighing options.

These examples of the growing recognition of and investment in patient engagement and Shared Decision Making are significant steps forward in creating a high quality patient centered health care system in the US. Together with the Supreme Court's recent confirmation of the key elements in the *Affordable Care Act*, we can point to some progress towards quality care improvement and access for all.

4 BREAST CANCER PUBLIC POLICY

2012

2011

4 | BREAST CANCER PUBLIC POLICY

From 1991 to 2012, over 870 resolutions and bills with the words "breast cancer" were introduced in the United States Congress.¹ That figure includes all resolutions and bills that contained the words "breast cancer." Other policies that had an effect on breast cancer but did not specifically reference the disease are not included in the total. This would include, for example, the legislation required every five years to reauthorize the prescription drug user fee program, commonly referred to as PDUFA, which gives the Food and Drug Administration (FDA) the authority to collect fees from the pharmaceutical industry and to use the revenue to support "the process for the review of human drug applications." Of the hundreds of resolutions and bills introduced, 11 resolutions were agreed to by the House and Senate, and 44 bills became law. About 40% of the resolutions, laws, and executive actions focused on the intertwined topics of breast cancer awareness and mammography. Another 42% focused on breast cancer specific research funding, mainly through the Department of Defense Breast Cancer Research Program (DOD BCRP). The remaining percentage were laws in the areas of access and research.

Looking at the activities of the 112th Congress, it is instructive to first look at the wider scope of all legislation, not just that related to breast cancer or even health care. As of July 2012, the 112th Congress had introduced over 9,500 pieces of legislation, including the <u>Accelerating the End of Breast Cancer Act</u> (S. 3237/H.R. 3067). Yet only 150 have become law.

Over 50% of these bills (77) have fallen into the following categories of legislation: 23% honored an individual or group by naming something (a courthouse, post office, etc.) after them; 13% extended existing laws; 8% appropriated funding for the federal government or extended funding through continuing resolutions; 7% either were required annual authorization bills (defense and intelligence), Free Trade Agreements or named individuals to serve on commissions, etc.





Data Source: The Library of Congress. THOMAS. ONLINE. 2012. Library of Congress. Available from: http://thomas.loc.gov/home/LegislativeData.php [stage in legislative process – signed by President] (Accessed July 30, 2012).

Of the remaining 73 bills passed so far by the 112th Congress, the only bill dealing directly with public health issues was H.R. 2005, the *Combating Autism Reauthorization Act* in May of 2011. The only other bills dealing with issues generally related to health care policy were the Food and Drug Administration (FDA) *Safety and Innovation Act* (S. 3187) which reauthorized PDUFA and S. 384, which reauthorized the semi-postal breast cancer awareness stamp.

5 | BREAST CANCER RESEARCH

2014

5 | BREAST CANCER RESEARCH

As outlined in the 2011 Baseline Report, billions in public funding, private investment and charitable contributions have been directed toward decreasing the burden of breast cancer over the last several decades, but the investment has not paid off in dramatic improvements in incidence or mortality from the disease. This year's report takes a closer look at the areas of resource allocation. The report focuses on the largest funders of research for which there is transparency and consistency in categorization of the research and thus allows for comparison.

Research is coded, often by the investigators themselves, into seven broad areas of scientific interest in cancer research as delineated by the *Common Scientific Outline (CSO)*. The common coding system of the CSO was developed in 2000 through a collaboration of US and UK cancer funding organizations.¹ The seven broad areas include biology; etiology (causes of cancer); prevention; early detection, diagnosis, and prognosis; treatment; cancer control, survivorship, and outcomes research; and scientific model systems. Research included in the biology category looks at the biology of how cancer starts and progresses as well as normal biology relevant to these processes. Research on etiology aims to identify the origins of cancer—genetic, environmental, and lifestyle—and the interactions among these factors. Research included under treatment focuses on identifying and testing treatments administered locally (such as radiotherapy and surgery) and systemically (treatments like chemotherapy which have an impact throughout the body) as well as non-traditional (complementary/ alternative) treatments (such as supplements, herbs, etc.). Research into the prevention of recurrence is also included under treatment.²

The US Government continues to be the largest funder of breast cancer research in the US. In 2010, the most recent year with complete data, the National Cancer Institute directed \$631,228,554 to breast cancer research. Approximately half of that research was directed at areas relevant to women after the disease has appeared—early detection, treatment of primary and metastatic breast cancer, survivorship, and outcomes research (Figures 5-7). Sixteen percent of the funding was directed at looking at the causes of breast cancer, nine percent at prevention, and approximately one-fifth of the funding was directed at understanding the biology of the disease.



Figure 5. NCI Overall Funding with Breakdown within Biology

Data source: National Cancer Institute Funded Research Portfolio, 2010



Figure 6. NCI Overall Funding with Breakdown within Etiology

Data source: National Cancer Institute Funded Research Portfolio, 2010



Figure 7. NCI Overall Funding with Breakdown within Prevention

Data source: National Cancer Institute Funded Research Portfolio, 2010

As shown in Figure 5, almost half of the research within the study of breast cancer biology is focused on looking at genomics, including the study of genes that turn on and turn off tumor growth. Six percent of total funding was directed at understanding the biology of cancer progression and metastasis; 1% was directed at investigating normal functioning; and 2% in development of resources and infrastructure for biology research.

Within the area of etiology (Figure 6), the focus of 7% of total funds is on building an infrastructure and resources for looking at the causes of the disease. Six percent is focused on endogenous causes, or factors within the body, and 2% on exogenous factors, or those outside the body. Another 2% of total breast cancer research funds allocated in 2010 by NCI was focused on the interactions of genes with both endogenous and exogenous factors.

Within the area of prevention (Figure 7), the NCI directed 5% of total funds to developing the infrastructure and resources for prevention, and 1% or less was allocated each to vaccines, chemoprevention, nutritional science, personal behaviors and complementary or alternative approaches.

The federal government also funds significant research through the Department of Defense Breast Cancer Research Program (DOD BCRP). The DOD As shown in Figures 8-10, one-fourth of the 2010 DOD BCRP grants were awarded for treatment research, and approximately one-half were for research on the biology of the disease, which included research on progression and metastasis (25%) and on initiation of disease (24%). Another 8% of overall funds was directed at research on the causes or etiology of breast cancer and 2% toward prevention research.

BCRP was created in 1992 as a result of the National Breast Cancer Coalition's "\$300 Million More" campaign to increase federal funding for breast cancer research. Due to NBCC's grassroots advocacy and the DOD BCRP's demonstrated success, Congress has approved funding for the program each year since. In 2010, the DOD BCRP



Figure 8. DOD BCRP Overall Funding with Breakdown within Biology

Data source: Department of Defense Breast Cancer Research Program: Funded Research, FY 2010

funded research grants totaling \$138,140,762. As shown in Figures 8-10, one-fourth of the 2010 DOD BCRP grants were awarded for treatment research, and approximately one-half were for research on the biology of the disease, which included research on progression and metastasis (25%) and on initiation of disease (24%). Another 8% of overall funds was directed at research on the causes or etiology of breast cancer and 2% toward prevention research.



Figure 9. DOD BCRP Overall Funding with Breakdown within Etiology

Data source: Department of Defense Breast Cancer Research Program: Funded Research, FY 2010





Data source: Department of Defense Breast Cancer Research Program: Funded Research, FY 2010

The largest private funder of breast cancer research is Susan G. Komen for the Cure. In 2011, the organization awarded \$57 million in grants. As shown in Figure 11, 22% of the total grants were directed toward treatment research, and 41% towards understanding the biology of the disease. Susan G. Komen for the Cure does not have the grants coded by subcategories such as metastasis.



Figure 11. Susan G. Komen for the Cure: 2011 Research Grants

Data source: http://ww5.komen.org/2011researchgrants.html

As outlined in the 2011 Baseline Report, significant resources are directed at breast cancer drug development through the pharmaceutical industry, but the specifics are not presented publicly. ClinicalTrials.gov collects information about federally and privately supported research once it reaches the clinical stage. On March 26, 2012, there were 123,184 clinical trials listed; 4,281 were listed as breast cancer trials and 35% (1,538) of these were listed as trials for metastatic breast cancer.

Editor's Note (September 2013): In determining the breakdown of research funding, the percentages used in this section reflect the number of grants coded in each category divided by the total number of grants awarded. It should be noted that for the NCI grants, the total number of grants used for the calculation is larger than the total number of grants awarded for the year as a significant number of awards are coded in more than one CSO category.

2014

201

6 | BREAST CANCER ADVOCACY

As described in the 2011 Baseline Report, breast cancer advocacy began as a grassroots effort to bring breast cancer to the national agenda during the 1980s. The Susan G. Komen Breast Cancer Foundation was founded in 1982, with a focus on promoting awareness and early detection. The National Breast Cancer Coalition (NBCC) was founded in 1991 by women who sought to go beyond awareness and mammography to end the disease. Today, there are hundreds, if not thousands, of non-profit groups in this country that focus on breast cancer, with advocates involved in a wide range of activities, ranging from helping to shape the breast cancer research agenda and federal and state legislation, to serving as liaisons between patients and physicians.

During the past year, women's health issues, including funding for breast cancer screening, were embroiled in controversy. The nature and extent of the fallout, both on political support for women's health issues, and on fundraising around breast cancer and other women's issues, remains to be seen. Susan G. Komen for the Cure experienced significant public relations challenges as a result of its decision in early 2012 to withdraw, and then restore, grant funding eligibility to Planned Parenthood. By late spring, there were indications that the incident had impacted the fundraising results for Komen events, but it is too early to assess whether fundraising by other breast cancer organizations will be affected. It is also still unclear of the impact on breast cancer cause marketing during the upcoming National Breast Cancer Awareness Month in October.

The year saw wider acceptance of **Breast Cancer Deadline 2020**[®] as a tool for bringing attention to eradicating the disease. The number of organizations endorsing **Breast Cancer Deadline 2020**[®] has grown to more than 100. The <u>list of endorsing organizations</u> includes many within the breast cancer community, as well as groups focused more broadly on women's health or other women's issues.

7 | MEDIA ANALYSIS

2011

7 | MEDIA ANALYSIS

7.1 INTRODUCTION

The baseline **Breast Cancer Deadline 2020**[®] Progress Report did not address media coverage of breast cancer issues. This year's report includes an analysis of breast cancer coverage during 2011 National Breast Cancer Awareness Month (NBCAM), because understanding the current conversation around breast cancer issues will be important in shifting the status quo and achieving greater progress.

The media plays an important role in shaping public perception of issues. Media coverage of breast cancer has increased significantly since Betty Ford first brought the disease into the public sphere in the mid 1970s,¹ and October was established as National Breast Cancer Awareness Month in the mid 1980s. Now articles can be found covering the disease almost every day of the year.

The goal of NBCAM was to promote mammography, and early coverage focused almost exclusively on encouraging screening. It was assumed that all breast cancers were the same, and if caught early, death from the disease could be prevented. Scientists have discovered much more about the disease since those early years—it is now known that all breast cancers are not the same and that tumor biology is more important in determining outcomes than the size of tumors. Research has also shown that aggressive tumors are often interval tumors, showing up in between mammography screenings. But has the narrative of breast cancer in the media changed?

Studies have demonstrated that women overestimate their lifetime risk of developing breast cancer⁵ and their risk at a young age^{4,6} based on what they hear and read. Various analyses show that past media coverage often gave incorrect messages about the complexity of breast cancer, the age at which women are at highest risk, the progress made and the importance of early detection.

A survey of popular US women's magazines in 2007 by artist, writer, and activist Lucinda Marshall reported that "October issues of the traditional women's magazines are offering overly simplistic information about breast cancer risk factors and tips

for preventing it".² Furthermore, she found that inspiring survivor stories far outweighed stories depicting the detrimental impacts on quality of life and the reality of fighting the disease.²

The average age of diagnosis is significantly misrepresented in the media. More than a decade ago, researchers conducted a study of how the increase in breast cancer incidence during the 1980s and 1990s was represented in popular magazine articles.³ With more than 85% of the articles, anecdotes, or case stories portraying women younger than fifty years of age when diagnosed with the disease, they concluded that "the popular press paints a picture of a plague that predominantly is striking young, professional women"³ though the reality is that the average age of diagnosis is over sixty. In an analysis of US magazine articles from 1993-1997, Burke and colleagues found that 84% of the personal stories were of women diagnosed before fifty years of age, with more than half of those being diagnosed prior to age forty.⁴ Merely 14% of articles presented factual information about age as a risk factor for breast cancer.⁴

This inaccurate narrative has had an impact on the public's perception of disease risk. Studies have demonstrated that women overestimate their lifetime risk of developing breast cancer⁵ and their risk at a young age^{4,6} based on what they hear and read.

While Marshall found an overemphasis on prevention tips in women's magazine articles on breast cancer,² Atkin and colleagues reported around the same time that leading newspapers, newsmagazines, and television networks focused their coverage on breast cancer treatment with less emphasis on prevention.⁷ "Prevention-oriented content is overshadowed by a heavy flow of stories about effective new treatments," write the authors. Moreover, personal narratives of cancer patients were featured in twice as many stories as data and statistics.⁷

The media's preference for stories on "effective" new treatments perpetuates the misperception that scientists are close to a cure for cancer. The mass media prematurely reports progress that is not yet ready for public consumption. Such progress is then equated with being one step closer to the cure. News stories about research presented at scientific meetings often omit basic study facts and cautions, and fail to acknowledge the preliminary stage of the research.⁸ As a result, the public is misled to believe that the scientific community is on the verge of major breakthroughs. As Woloshin, Schwartz, and Kramer illustrate,⁹ NBC news coverage of the results of a phase I uncontrolled study of olaparib,¹⁰ a PARP inhibitor, began with "...some are calling this the most important cancer breakthrough of the decade."¹¹ However, it is not just the journalists who contribute to this problem. When press releases issued by academic medical centers included investigator quotes, nearly one-quarter of the quotes were found to exaggerate the importance of the results.¹² Gary Schwitzer's *HealthNewsReview.org* reviews the accuracy and reliability of news stories that make a therapeutic claim about specific treatments, tests products or procedures. A multi-disciplinary team of reviewers from journalism, medicine, health services research and public health, as well as advocates, assesses the quality of each story using a list of ten criteria including whether it addresses cost, harms and benefits, the quality of the evidence, and whether it avoids conflict of interest by seeking out independent sources.

How much does this media coverage influence women? It is well known that the general public relies on the media as important sources of health information.^{13,14} Media exposure is positively related to perceptions of personal risk,¹⁵ such as the incorrect perception that all young women have a high risk of breast cancer and a high cure rate. Recently, media coverage played a large role in the public's opinion of the US Preventive Services Task Force (USPSTF) mammography screening guidelines issued in 2009. An analysis of the public's response revealed that the new recommendations confused more than helped women.¹⁶ Women's skepticism of the new mammogram guidelines was increased by exposure to negative media.⁵ For women forty years of age and older, their decision to get a mammogram relies more heavily on media coverage when they do not have regular contact with or access to physicians;¹⁷ a large percentage of the poor and underserved in the US fall into this group.

What is the breast cancer conversation today? Has the media portrayal begun to change at all in response to **Breast Cancer Deadline 2020**®? This analysis presents an overall picture of the breast cancer narrative in the media during the 2011 NBCAM. Is it accurate? Or is it creating a false narrative that distorts reality, increases fears, creates barriers to progress, and makes it more difficult to have the right conversations about ending the disease?

7.2 ANALYSIS

NBCC conducted an analysis covering one month of news coverage in the US during the 2011 NBCAM: October 1-31, 2011. It was restricted to the five US newspapers with the largest circulation to capture high-visibility reporting: USA Today, The Wall Street Journal, The New York Times, The Los Angeles Times, and The Washington Post. The four women's magazines with the largest circulation were also included in order to focus on sources of impact on those with or at risk of breast cancer: Better Homes and Gardens, Good Housekeeping, Woman's Day, and Ladies' Home Journal. Television and radio news coverage was not included.

Newspaper articles were identified by searching Lexis-Nexis using the key word 'breast cancer' within the date range from October 1, 2011 to October 31, 2011. Of the four magazines, *Good Housekeeping* was the only one available in Lexis-Nexis, so October 2011 issues of the remaining three magazines were obtained from local

libraries. Two readers independently coded each article according to a coding instrument that asked the reader to indicate the presence or absence (yes/no) of specific elements in the story (elements were not mutually exclusive). The coding instrument included the following questions:

- 1. Does the article include a personal story? If so,
 - What was the age of the person when diagnosed?
 - Did the person have a family history of breast cancer?
 - Was the person experiencing a primary breast cancer, a metastatic breast cancer or a recurrence?
- 2. Is the article about treatment?
- 3. Is the article about prevention/risk factors?
- 4. Is the article about screening? If so,
 - Does it give the message that 'early detection saves lives?'
 - Does it present a balanced view with limitations of screening?
- 5. Is the complexity of the disease portrayed in the article? Specifically, does it explain that not all breast cancers are the same, that there are different subtypes, associated with different risks and lifestyle behaviors?
- 6. Does the article address eradication of disease? Does it speak of ending the disease? If so,
 - Does it mention Breast Cancer Deadline 2020®?

News items and magazine stories were not included in the sample if they did not specifically cover breast cancer. A story was excluded if it focused on multiple types of cancer, was about cancer in general, or if it simply mentioned that an individual had breast cancer but was about a different topic. Also excluded were articles such as "Think pink in October for breast cancer" in *USA Today* because it was about donations and items for sale to raise money for the cause.¹⁸ Articles about insurance coverage changes, such as an article announcing that Blue Shield of California will no longer cover Avastin[®] for breast cancer, were excluded. An article which

simply gave tips on what to do the day of a mammogram was also excluded. Letters to the editors, obituaries, reader forums, film/television reviews, and advertisements were not included.

The coders resolved disagreements through discussion. When disagreement persisted after discussion, a third independent coder was the deciding factor. The individual story was the unit of analysis.

7.3 RESULTS & DISCUSSION

A total of 28 news items and seven magazine stories that appeared in the selected newspapers and magazines during October 2011 were included in this analysis. The number of articles on breast cancer in each news source is listed in Table 1. In three instances, a third coder was necessary to resolve coding disagreements; two out of the three times the discrepancy involved answering the question 'Does it give

Newpaper articles	Number of articles	
Total	28	
USA Today	9	
The Wall Street Journal	4	
The New York Times	8	
The Los Angeles Times	6	
The Washington Post	1	
Magazine articles		
Total	7	
Better Homes and Gardens	1	
Good Housekeeping	2	
Woman's Day	2	
Ladies' Home Journal	2	

Table 1. Number of articles selected from each newspaperor magazine source during October 2011





* Categories are not mutually exclusive.

the message that 'early detection saves lives?' Figure 12 shows the overall emphasis identified for the 35 articles.

Prevention/risk factors was the most common theme across all articles, with 31% focusing on this subject. Among the seven magazine stories that month, none were about treatment and two were focused on prevention or risk factors, though not necessarily evidence-based information. In *Woman's Day*, the article, "10 ways to protect against breast cancer," claims that doing breast self-exams, limiting alcohol intake, not smoking, and watching your weight are important ways to lower your breast cancer risk.¹⁹ "19% is how much you'll lower your breast cancer risk if you're overweight and lose at least 20 pounds." According to this article, women can greatly lower their risk or avoid the disease all together by taking ten simple actions or lifestyle changes. Though observational studies have shown an association with some of these factors and increased risk, the article fails to note that no scientific evidence has demonstrated that women can significantly lower their risk or avoid the disease.

Twenty-five percent of articles discussed screening in depth, and 20% treatments, old and new. Six of the nine articles that went into detail on screening mammography presented a balanced view of screening with its limitations. This shows that the harms of mammography, including radiation, unnecessary biopsies, anxiety and overdiagnosis, are being shared with the general public. In a USA Today article, the author quantifies the harms in a statement from a researcher and physician:

"....mammograms' benefits must be balanced against their risks. In a group of 10,000 women screened with mammograms, up to 2,000 will have an unnecessary biopsy, and up to 50 will get unnecessary treatment because a mammogram detects a slow-growing tumor of a type that would never prove life-threatening."²⁰

Seven articles accurately reported that not all breast cancers are the same. These articles portrayed the complexity of the disease, with statements such as:

"Some doctors are optimistic that by learning more about the molecular characteristics of breast cancers, they'll be able to classify them more narrowly and do a better job of matching tumors to

treatments. That could make certain types of breast cancer as manageable as chronic illnesses like diabetes, they say."²¹

"...her cancer turned out to be one of the most difficult types to treat and cure. The tumor cells lacked receptors for estrogen and progesterone that are associated with more curable cancers, but the cells carried receptors for HER-2/neu, a growth factor associated with aggressive disease."²²

Nineteen articles (54%) included one or more personal stories. Within the nineteen articles, 24 personal stories shared the age at diagnosis (four unknown ages): merely three of the women were over 60 years of age at diagnosis, and the oldest age for a primary breast cancer diagnosis was 57. This does not reflect reality: 50% of breast cancer occurs in women aged 62 and older. It comes as no surprise that young women who read these 'news' reports throughout the month believe they have a much higher risk of the disease than they actually do.^{4,6}

The majority of personal accounts were primary, early stage, breast cancer diagnoses. Often times, a picture was painted of survivors who are disease-free and overcame the disease:

"...I don't want to say I just survived cancer. I want to say I kicked its butt and watch me now!" 23

Too often, many in the media gravitate toward stories that are extremely hopeful. However, there was a handful that told the story of women with everyone's biggest fear—metastatic disease. Four articles portrayed one or more women battling this deadly diagnosis. NBCC President Fran Visco was quoted in a USA Today article sharing the reality of Stage IV disease:

"In October, and year-round, we paint breast cancer as very pink and pretty, and we don't talk about the fact that we haven't made much progress against Stage 4 disease."²⁴

Although many articles were about survivors, several discussed long-term side-effects of treatment and the impact on quality of life. Persistent fatigue, depression, and "chemo brain" were among the many delayed side-effects of breast cancer treatment that were acknowledged in the stories, and the need for better survivorship care and "rehab" was a recurring theme in several articles.^{25,26} This may be seen as a slight improvement over a prior finding that inspiring survivor stories far outweigh stories depicting the detrimental impacts on quality of life and the reality of fighting the disease.² To reduce the risk of recurrence and improve quality of life, women were told to exercise. The effect of exercise on the tumor microenvironment, specifically in preventing chronic inflammation, was a popular topic.²⁷

Of the three magazine articles that focused on screening, none promote early detection as a life saver.

"Countdown to the Cure," an article in *Ladies' Home Journal* about **Breast Cancer Deadline2020**[®], was the only article to mention ending breast cancer.²⁸ Keys to ending the disease—understanding primary prevention and how to prevent Continuing to push for accurate coverage of breast cancer in the media and attention to the areas that will lead to eradication of the disease is a priority for **Breast Cancer Deadline 2020**[®].

metastasis—are not receiving significant coverage. There are stories about new drugs and ways for survivors to improve their quality of life, but little about the important priority of preventing breast cancer in the first place. While progress is being made, changing the conversation in the media remains a challenge. Continuing to push for accurate coverage of breast cancer in the media and attention to the areas that will lead to eradication of the disease is a priority for **Breast Cancer Deadline2020**[®].

8 | ADVOCATE PERSPECTIVE

2014

8 | ADVOCATE PERSPECTIVE

In NBCC's 2011 Baseline Report we gave our advocate perspective on the state of breast cancer. As that perspective described, there has not been sufficient progress in any area of breast cancer—treatment, prevention, quality care, public policy—over the past many decades. Save one: there are booming breast cancer industries in both the for- and non-profit fields that seem primarily focused on their own survival rather than the goal of ending breast cancer. There is no need to repeat that perspective here, as the Baseline Report remains the best statement of our positions.

That is the case because as this 2012 report makes clear, little has changed. There was never an expectation by advocates that one year would "turn it all around." The Baseline Report described the status quo that has been developed over more than 40 years and has been designed to achieve incremental, if any, progress. As a result, looking at the existing infrastructure and business of breast cancer one would expect to see exactly what happened: there have been no significant changes in preventing, finding, treating or curing breast cancer over the past year. The one major exception is NBCC's **Breast Cancer Deadline 2020**[®] campaign which has progressed rapidly as is highlighted in this 2012 Progress Report.

As advocates, we believe we must begin talking about breast cancer issues differently. This past year saw a controversy over access to screening dominate not just breast cancer news stories but also the general news cycle. Susan G. Komen for the Cure's decision to withdraw, and then restore, grant funding eligibility to Planned Parenthood was front page news. The conversation was often couched in terms of a concern over whether Planned Parenthood's constituency would have access to screening. The uproar shows that there is still such a strong belief in the value of mammography screening, despite years of research showing marginal benefit at best. The fallout from that controversy is not yet fully understood.

The good news is that, despite the media focus on this controversy this past year, the conversation is beginning to change in the advocacy and scientific communities, away from awareness and early detection, and a focus on the cell, to ending breast cancer. In science, an overwhelming amount of research continues to focus on the genes involved with cancer, and even on mutations involved with the deadly spread of breast cancer. Entire

research programs that span several years are established and flourish around the discovery of these mutations. These efforts held promise, received funding, have led to publications and career development, and fueled the pipelines of Pharma and biotech companies. But we now know, after many years, that these efforts are not likely to lead to anything more than incremental improvement for patients, and it is time to expand that focus. Tumors are constantly evolving, and targeting particular mutations is maybe nothing more than a stop-gap, temporary solution. Rather than focusing on

Advocates must not take the easy way out, accepting sound bites as answers. In order to move forward toward the goal of **Breast Cancer Deadline 2020**[®], it is necessary to do the hard work of critically analyzing policies and research and challenging the status quo in a meaningful way.

the tumor cells and on mutations, NBCC believes that science should look at the whole system in which cancer develops, within and without the body, to gain an understanding of why and how it develops and spreads, and with an eye toward learning how to intervene and prevent deaths. We have seen science move a bit in this direction, toward asking big questions that could have real impact.

Advocates must not take the easy way out, accepting sound bites as answers. In order to move forward toward the goal of **Breast Cancer Deadline 2020**°, it is necessary to do the hard work of critically analyzing policies and research and challenging the status quo in a meaningful way. That critical analysis must apply to all issues in breast cancer, including drug approval, the substance of the research, the priorities set, the allocation of funding, and access to care.

For example, while science and the conversation may slowly be moving in the right direction, there is still too strong a push on getting more drugs to the clinic with insufficient evidence of real benefit. If we are told the FDA takes too long and makes it too difficult to approve a drug, we should look carefully at the facts. What do we want from breast cancer drugs? Short of a cure, we want significant improvement in overall survival and quality of life. What are we willing to pay in terms of toxicity and financial burden? Then we must ask what approval process is needed to make certain we have access to drugs that meet our standards.

This past year, primarily because of the reauthorization of PDUFA, the program that gives the FDA the authority to collect fees from the pharmaceutical industry to support the drug review process, it appeared that there was an increase in campaigns to make it easier to get drugs approved. This push for approval earlier in the research process, with preliminary results that fall short of clinical impact, seems to be growing, despite the lesson learned from the accelerated approval of Avastin and its subsequent withdrawal. The lesson learned by NBCC advocates from that story was that stronger evidence of real benefit—overall survival and quality of life—and a better understanding of risks must be demonstrated before a drug is approved. One important part of the Avastin story that seems to be overlooked is that, in large part because of accelerated approval, Avastin

One area of apparent progress can be attributed directly to the efforts of the advocacy community. In reports of government breast cancer funding, there are currently significantly more dollars devoted to metastasis research.^{1,2} However, as in every area of research, it is important to look critically at how these dollars are spent. was given to many women with early breast cancer, and we now know that it not only had no benefit but also did harm. While NBCC applauds the FDA's withdrawal of approval for Avastin, accelerated approval in the first place meant more women were harmed, more health care dollars were spent on an ineffective drug, and more individuals and policy makers, reacting headlines, fought to overturn the FDA's decision and undermine its credibility.

It is our perspective that the failure to look more critically

at data and information also extends to various analyses of research funding. One area of apparent progress can be attributed directly to the efforts of the advocacy community. In reports of government breast cancer funding, there are currently significantly more dollars devoted to metastasis research.^{1,2} However, as in every area of research, it is important to look critically at how these dollars are spent. Just as funneling significant dollars to breast cancer research created a breast cancer research industry that has not resulted in sufficient progress, it would be counter-productive to create a "metastasis" research industry that does not result in meaningful results for patients. Just labeling a research proposal as "metastasis" is not enough. We must take a critical look at the research and encourage only those efforts with the highest potential for meaningful outcomes for patients. We must ask different questions and apply a new perspective. Will finding a gene mutation that suppresses or drives metastasis in a subset of women be enough? Is this really different from the majority of research looking into tumor suppressor genes and the like? Do we know whether targeting a mutation with a drug would provide more than a few weeks or months of additional life for a subset of women?

How devastating would the side effects be to a person's quality of life? And how can we prevent metastasis? How can we understand its causes? We should be willing to look at this issue from different perspectives because the

Research into the causes of breast cancer has proven difficult in the past, but new knowledge and new tools must be applied in a concentrated effort at understanding the development of the disease. current thinking has not given us the answers we need.

While it is clear that more dollars are being reported as allocated to metastasis research, the area of prevention research has not benefited in the same manner. Research focused on primary prevention is receiving a much smaller portion of the pie than metastasis research.^{1,2} Many people still believe that breast cancer screening is prevention, or at least will prevent deaths from breast cancer. Research

into the causes of breast cancer has proven difficult in the past, but new knowledge and new tools must be applied in a concentrated effort at understanding the development of the disease. Much of the past work assumed breast cancer was one disease. Applying new tools for bioinformatics with new knowledge of the immune system and subtypes of breast cancer will be key in achieving **Breast Cancer Deadline 2020**[®].

As laid out in this report, we, advocates, are leading a campaign to end breast cancer. But we cannot do it alone. All advocates who share that goal must reach out to their networks, their communities and contacts to bring all stakeholders into the **Breast Cancer Deadline 2020**[®] campaign. Over this year we must significantly increase the number of groups and individuals who are part of the campaign and make certain that leaders in government, industry and all areas embrace the deadline with courage and conviction to make ending this disease a priority. From the halls of Congress to the laboratories and boardrooms, the approach to breast cancer must change. And, this effort cannot be just a national effort; global networks, leaders and stakeholders will need to be engaged. More stakeholders—in the US and abroad—must join in the collaborative and catalytic work on the Artemis Project[®] to leverage existing financial resources and harness the knowledge and experience of years of research. The goal is to take what is known and build upon it to catalyze innovation for the sole purpose of ending breast cancer.

BREAST CANCER DEADLINE 2020®

2014

9 | PROGRESS TOWARD BREAST CANCER DEADLINE 2020®

Breast Cancer Deadline 2020[®] is a global plan of action to end breast cancer. This will require a paradigm shift in the breast cancer world to change the conversation and to refocus resources and efforts to the key areas of:

- > Primary Prevention: How do we stop people from getting breast cancer?
- > The Causes & Prevention of Metastasis: How do we stop people from dying of breast cancer?

The four specific strategies that NBCC is using to reach this goal are:

- · Research, including new strategies and collaborations
- A public policy approach, including federal legislation and a plan to ensure worldwide access to lifesaving interventions
- Grassroots advocacy and education of a large corps of activists around the globe to engage their communities
- Communications & media outreach to change the conversation to ending breast cancer by 2020

During the past year, NBCC began to implement a strategic plan of action in each of the four areas. Specific achievements are outlined below.

9.1 RESEARCH

NBCC is leading an effort to facilitate collaboration among stakeholders involved in breast cancer research, particularly the scientific community, in order to create synergy and develop partnerships to advance the pace of research. NBCC hosted summits to assess key problems in breast cancer, identify meaningful questions and determine the individuals and tools needed to answer them. Priority issues identified through summits and other **Breast Cancer Deadline 2020**[®] work are the subject of catalytic projects, collectively known as

the Artemis Project[®].

Artemis Project[®]: Identifying the Questions and Developing Plans

Through the Artemis Project[®], NBCC has created an innovative, advocate-led, mission-driven model, which ensures appropriate focus on the end result. NBCC launched the Artemis Project[®] in 2011 to

Through the Artemis Project®, NBCC has created an innovative, advocateled, mission-driven model, which ensures appropriate focus on the end result.

bring together a collaborative group of advocates, scientists, and other stakeholders to take a strategic, systematic, yet broad approach to overarching issues. For each issue, NBCC will lead efforts to form innovative collaborations to identify problems, define solutions and implement plans to achieve them. The participants in these project collaborations will design and implement research plans, and NBCC will award seed grants to begin the necessary work. The majority of the research will be funded by leveraging

outside, existing resources such as government, private foundations, and corporations. NBCC will establish an infrastructure that allows the collaborations to thrive and progress rapidly. This model will be replicated to advance other identified priorities within the two key areas of primary prevention and the causes and prevention of metastasis.

Artemis Project[®]: A Plan for a Breast Cancer Preventive Vaccine

The first project to arise from this work brings together a collaborative group of advocates, scientists and other stakeholders to design a five-year development plan for a breast cancer preventive vaccine. This project takes an unbiased look at what is already known and builds upon and harnesses that knowledge to create the safest vaccine that actually works to prevent breast cancer in women.

Four issues were identified as central objectives for the development of a vaccine. NBCC established a project team of scientists and advocates to work on each and across all:

- Search for a virus(es) or antigen target(s) that will be safe, effective, and provide broad coverage for a diverse population of women.
- Determine how the immune system responds to breast cancer with the aim of determining what the vaccine needs to accomplish.
- Design appropriate clinical trials taking into account the optimal time for intervention and the appropriate population in order to achieve the highest impact and maximum results for those at risk of breast cancer.
- Develop a plan to address safety issues across all steps of the project.

In April 2011, NBCC convened scientists from academia and industry, including epidemiologists, immunologists, and computational biologists, as well as providers, clinicians and advocates, for the first annual Artemis Project[®] vaccine meeting. At that meeting, the participants began to develop the initial research agenda within the four primary identified focus areas.

Following the first annual meeting, NBCC prepared a <u>detailed strategic work plan</u> for the vaccine project, based on the outcomes of the meeting and follow-up interviews with attendees. This Project Plan was completed in December 2011.

In January 2012, NBCC issued a Call for Proposals to address the initial steps in antigen identification and prioritization, asking investigators to use computational and bioinformatics approaches to carry out a systematic analysis of existing and developing human genomic, proteomic, glycomic, or immune system profiling data within the context of human breast cancer. Letters of Intent were solicited in three areas:

- 1. Identification of breast cancer antigens in genomic and RNA expression data;
- 2. Viral and microbial gene expression in breast cancer; and
- 3. Identification of breast cancer antigens in human data obtained by proteomic, glycomics, or immune system profiling.

The second annual meeting was held March 3-5, 2012, in Calistoga, California, to assess progress in the field and within the project, and to adjust teams, projects, and focus as necessary. Meeting participants took a comprehensive look at antigen identification and developed strategies and models for determining what the vaccine needs to accomplish. The specific needs for antigen identification were refined and are reflected in the Call for Full Proposals issued to selected investigators in Spring 2012.

NBCC is working with National Philanthropic Trust to award an initial grant for antigen identification in the Summer of 2012, and to issue a second call for proposals for further antigen evaluation by the end of the year.

Strategic Summits on Primary and Secondary Breast Cancer Prevention

During 2011, NBCC held two strategic summits around the priority areas of primary breast cancer prevention and the causes and prevention of breast cancer metastasis. Recommendations from the Summits are not necessarily the steps that NBCC will incorporate into its work related to **Breast Cancer Deadline 2020**°, but they will inform the strategies adopted.

During 2011, NBCC held two strategic summits around the priority areas of primary breast cancer prevention and the causes and prevention of breast cancer metastasis.

Strategic Summit: Causes and Prevention of Metastasis

The Summit on Prevention of Metastatic Breast Cancer was held August 26-28, 2011, in Aspen, Colorado. NBCC gathered a diverse group of breast cancer advocates, scientists, and clinicians from across the United States, Canada and Europe to begin to outline a research plan of action for the prevention of metastasis.

Investigators currently looking at the biology of

breast cancer metastasis—the genetics, the cellular mechanisms, and the role of the immune system were brought together with investigators who have different perspectives, such as those who have created mathematical models of metastasis, who are examining lifestyle effects, or who have been applying evolutionary theory to cancer progression, along with those who work outside of the field, such as physicists.

During the meeting, participants divided into groups to discuss the breast cancer metastatic process what we know, what we need to know, creative approaches for prevention, how different approaches can complement one another, and finally, what we need to do to move forward to achieve progress for women.

Each group took a slightly different approach and their proposals are summarized as follows:

- A consortium of institutes aimed at developing a multi-faceted approach to prevention of metastasis for those at highest risk, based on the idea that multiple interventions will work better and prevent resistance. The consortium would focus on three areas: multidisciplinary research projects to develop interventions reflecting a variety of approaches, such as targeting dormancy, the immune system, lifestyle interventions, or the tumor environment; biomarker development focused on identifying which patients are likely to benefit most; and multiple, small, "secondary prevention" clinical trials with adaptive designs to look for large effects and to collect tissue at regular intervals for information to be fed back into intervention and biomarker development.
- Understanding what occurs between primary diagnosis and breast cancer spread or metastasis. The group identified several key research questions about the role of breast cancer cells and the host in tumor dormancy and metastasis, and important areas for clinical translation, including developing technologies to detect the first signs of metastasis.
- Improved imaging, exploration of biomarkers, tissue collection, and whole-genome sampling to identify host factors; a large, prospective, longitudinal cohort study, to follow women from the time

of diagnosis, comparing those who develop distant metastases with those who do not; and exploring the repurposing of approved drugs, investigational drugs, and other interventions to develop less toxic treatments.

Strategic Summit: Primary Prevention

The Summit on Primary Prevention of Breast Cancer was held October 1-3, 2011, in Aspen, Colorado. A diverse group of 35 breast cancer advocates, scientists, and clinicians, with a variety of perspectives on cancer prevention, attended the Summit. Participants included long-time advocates in women's health, a biomedical engineer, epidemiologists, biochemists, evolutionary biologists and endocrinologists, along with breast cancer clinicians and surgeons. The group included a director of a center for the study of breast cancer and the environment, as well as principal investigators from several major studies in prevention, including studies of chemoprevention, exercise and diet and breast cancer risk, and a large study of cancer and diet in China.

During the meeting, participants divided into multidisciplinary groups to debate and discuss strategies for breast cancer prevention. Strategies discussed included:

- Targeted prevention—broaden the concept and change the conversation around chemoprevention by developing validated and more precise risk tools, mechanisms to target, and agents.
- Transformative lifestyle change (TLC)—modifying lifestyle factors, such as diet, exercise, and stress, particularly in combination, would provide some prevention benefit with no harm.
- Pseudo-pregnancy to mimic hormonal changes that offer protection against post-menopausal breast cancer.
- Develop a strategy to avoid the harmful effects of persistent ovulation.
- Caloric restriction—developing drugs or lifestyle that lead to or simulate caloric restriction.
- Windows of vulnerability, to determine common changes that occur; study normal human processes, then compare that information with tissue from diseased individuals.
- Develop delivery systems, using nanotechnology to directly target breast epithelium.
- Vaccine approaches.

All of the conversations and issues raised during the various meetings of 2011 have informed NBCC's future plans and contributed to decisions about the next immediate steps needed to accelerate an end to breast cancer. NBCC is currently developing the foundation for several additional catalytic projects and other collaborative meetings of stakeholders in the next six to twelve months.

9.2 PUBLIC POLICY

All stakeholders play a key role in achieving the goals of **Breast Cancer Deadline 2020**°. The government and public officials are no exception. During the last year, NBCC's public policy work included a forum to educate Congress, meetings with White House officials, introduction of legislation and other strategies to educate and involve legislative and administration leaders.

Congressional Forum

On September 21, 2011, NBCC hosted a Congressional forum, *An End to Breast Cancer: Is it Possible?*, aimed at educating Members of Congress and their staffs about **Breast Cancer Deadline 2020**[®]. NBCC President

Fran Visco and Dr. H. Kim Lyerly of Duke University Medical Center reported on progress that has been made to end the disease, why a new approach to ending breast cancer is needed and the role NBCC and other stakeholders—including Congress—will need to play to achieve **Breast Cancer Deadline 2020**[®].

Legislation

Based on NBCC's public policy work over the past years and the feedback gleaned during a January 2011 Public Policy Roundtable, NBCC developed the first piece of legislation to support and complement the work of **Breast Cancer Deadline 2020**°. In September 2011, the <u>Accelerating</u> the End of Breast Cancer Act was In September 2011, the Accelerating the End of Breast Cancer Act was introduced in the US House of Representatives.... Companion legislation was introduced in the Senate in May 2012....

introduced in the US House of Representatives by Reps. Karen Bass (D-CA-33) and Charlie Bass (R-NH-02), along with Reps. Hanabusa (D-HI-01), Scalise (R-LA-01), Moore (D-WI-04), Capito (R-WV-02) and DeLauro (D-CT-03). Companion legislation was introduced in the Senate in May 2012 by Senator Sheldon Whitehouse (D-RI), along with Senators Grassley (R-IA), Brown (D-OH), Collins (R-ME), Shaheen (D-NH), Murkowski (R-AK), Warner (D-VA) and Heller (R-NV).

A vital component of **Breast Cancer Deadline 2020**°, the *Accelerating the End of Breast Cancer Act* will leverage the nation's past investments in biotechnology, biology and other areas related to breast cancer to accelerate the progress made towards ending the disease. Like **Breast Cancer Deadline 2020**°, the Act focuses on the primary prevention of breast cancer and preventing breast cancer metastasis. This approach will harness the nation's continued drive for innovation, and help ensure its position as the worldwide leader in medical and scientific advancement.

Declaration of Support from Public Officials

Shortly after the launch of the campaign, NBCC advocates began contacting those in office, elected, or appointed—federal, state, and local—to sign a declaration of support for **Breast Cancer Deadline 2020**[®]. These efforts continued throughout the past year. All officials have been asked for their public commitment to work with the National Breast Cancer Coalition to end breast cancer by January 1, 2020 by supporting **Breast Cancer Deadline 2020**[®].

Presidential Petition

In 2011, NBCC launched a petition drive calling on the President to bring this nation's leadership, intellectual and creative forces to bear on a matter of utmost importance to everyone, around the world. NBCC is gathering signatures on a <u>petition to the President</u> calling on him to commit to **Breast Cancer Deadline 2020**[®]. The petition signatures will be delivered to the President shortly after Inauguration Day—January 21, 2013.

Breast Cancer Caucus 2012

In all previous presidential campaigns since NBCC's inception in 1991, advocates have educated the candidates as well as the public about the importance of a political approach to ending breast cancer. In 2011, NBCC asked each candidate his position on NBCC's legislative and public policy priorities and to submit a short video answering the question, "Do you support **Breast Cancer Deadline 2020**®? And if so, as President, what would you do to achieve the goal of ending breast cancer by January 1, 2020?" Responses and videos are posted as they are received at BreastCancerCaucus.org.

9.3 GRASSROOTS ADVOCACY AND EDUCATION

NBCC's work to end breast cancer through the **Breast Cancer Deadline 2020**[®] initiative requires the involvement and leadership of educated breast cancer advocates worldwide. The <u>Center for NBCC</u> Advocacy Training has been a leader in supplying the education, tools, training and action that enable breast cancer survivors and other advocates to take leadership roles in clinical, scientific, policy and legislative decision making that affects breast cancer research. With the new focus and urgency of the **Breast Cancer Deadline 2020**[®] initiative, the Center for NBCC Advocacy Training plays a key role in training breast cancer advocates to work in their communities and side-by-side with scientists to change the conversation in breast cancer, set research priorities, and design and focus research on key areas that will end the disease by 2020.

Advocacy Training Conference

The 2011 NBCC Annual Advocacy Training Conference focused on **Breast Cancer Deadline 2020**[®] in order to engage nearly 1,000 attendees in the work of the campaign. All components of the conference were geared to teach advocates how to effectively shift the conversation on a national and local level to the single-minded purpose of ending breast cancer by January 1, 2020. NBCC introduced workshops devoted to NBCC's work to end breast cancer through the **Breast Cancer Deadline 2020**[®] initiative requires the involvement and leadership of educated breast cancer advocates worldwide.

working on **Breast Cancer Deadline 2020**[®] and provided a <u>Breast Cancer Deadline 2020[®] Toolkit</u> to each attendee. The Toolkit offered concrete aids to supplement the highly interactive workshops but also served as useful references for mobilization and outreach activities once the participants returned to their home communities. Toolkits were distributed to advocates across the country who did not attend the Conference and were also made available online to visitors to the NBCC website from around the world.

Project LEAD®

Project LEAD[®], NBCC's acclaimed science-training course for breast cancer advocates, equips an educated pool of activists with well-developed critical appraisal skills and a commitment to evidencebased health care that is essential to the success of **Breast Cancer Deadline 2020**[®]. The course is offered at two levels—an introductory course for all breast cancer advocates interested in learning more about science and a higher-level course for advanced training. In 2011, NBCC conducted introductory Project LEAD Workshops in Tampa, Florida and Seattle, Washington. The Project LEAD Institute, the intensive six-day course that covers the biology of breast cancer, genetics, epidemiology, research design and advocacy, was once again offered in La Jolla, California. The Institute curriculum went through a number of revisions in 2011 both in scientific content and focus to integrate the **Breast Cancer Deadline 2020**[®] research component.

Online Education

NBCC understands that many advocates are unable to devote the time and effort to participate in multi-day courses or educational programs in communities away from their home. In response, NBCC has ensured that much of the education and information shared as part of **Breast Cancer Deadline 2020**[®] is offered online. During the past year, NBCC offered online Team Leader Training to deliver high-quality public policy advocacy training to a larger leadership group. Graduates of Project LEAD were invited to three LEADCasts,

offering advanced education in areas of science and research. And NBCC's website, KnowBreastCancer. org, served as a central resource for breast cancer information with regularly updated news and research summaries related to breast cancer.

Local Action Networks

Breast Cancer Deadline 2020[®] Action Networks organize advocates by state or region to work collectively and build support, energy and momentum for **Breast Cancer Deadline 2020**[®]. Networks were established in Massachusetts, Illinois and Washington in 2011. These groups are developing and implementing action plans to engage and mobilize new advocates to broaden the reach for **Breast Cancer Deadline 2020**[®] within their states, expand local outreach efforts and broaden the base of supporters willing to push the envelope and demand actions to end breast cancer by the end of the decade. The networks serve as models for the other states and regions in this country, as well as continent-based networks across the globe.

Speakers Bureau

The NBCC Speakers Bureau was launched at the 2011 Advocacy Training Conference. These speakers, as well as NBCC leadership including the Board, have given presentations throughout the country over the last year in order to share information about **Breast Cancer Deadline 2020**[®] and engage more individuals in the work of the campaign.

Since the launch of Breast Cancer Deadline 2020[®], more than 100 organizations have endorsed the Campaign, and that number continues to grow. This expanding list of endorsing organizations demonstrates the breadth and diversity of the community that stands behind Breast Cancer Deadline 2020[®].

Organizational Endorsement

NBCC has been building support from a broad array of groups and organizations—not just those focused on breast cancer but all who care about and understand the importance of this issue that will help create the required sense of urgency needed to achieve the end of breast cancer. Since the launch of **Breast Cancer Deadline 2020**°, more than 100 organizations have endorsed the Campaign, and that number continues to grow. This expanding list of endorsing organizations demonstrates the breadth and diversity of the breast cancer, women's health and health care advocacy community that stands behind **Breast Cancer Deadline 2020**°.

9.4 COMMUNICATIONS AND MEDIA OUTREACH

NBCC launched an expansive effort to change the conversation around breast cancer to a dialogue about ending the disease by 2020.

31 Truths About Breast Cancer

NBCC's message to the media in October 2011 focused on **Breast Cancer Deadline 2020**[®] and its goals, as well as a daily message about the disease—the 31 Truths About Breast Cancer.

In order to make real progress toward saving lives and ending breast cancer—which is the goal of **Breast Cancer Deadline 2020**[®]—everyone needs to better understand the reality of this disease at all levels. Throughout October 2011, NBCC shared 31 Truths About Breast Cancer with the general public in order to move the conversation from awareness of pink ribbons to awareness of the facts about breast cancer. The 31 Truths remain available online in both English and Spanish at <u>BreastCancerDeadline2020.org/All31Truths</u>.

Media Project LEAD®

NBCC held a one-day session for health editors and writers of women's magazines, journals, general and social networking media on September 26, 2011 in New York. This Media Project LEAD was co-hosted by Peggy Northrop, then Editor-in-Chief of *Reader's Digest* and Cindi Leive, Editor-in-Chief of *Glamour*. Faculty members included Susan Troyan, MD, and Leslie Bernstein, PhD, who covered the biology and epidemiology of breast cancer. Three of the foremost experts in health media evaluation and communications, Gary Schwitzer, Lisa Schwartz, MD, and Steve Woloshin, MD, offered methods for best presenting evidence-based breast cancer information that is both understandable to the public, and statistically and contextually accurate and balanced.

Blogs and Other Online Media

The breast cancer conversation online started to evolve over the last year. Key bloggers in the breast cancer community attended the 2011 Advocacy Training Conference or participated in other educational programs related to **Breast Cancer Deadline 2020**[®]. In addition, NBCC offered a blogging workshop at the Conference and established a Blog Response Team to monitor and participate in the breast cancer

conversation online. NBCC President Fran Visco increased the frequency of her blog entries on *Huffington Post*.

Events and Meetings

In addition to the strategies related to traditional and online media, NBCC has endeavored to change the conversation in breast cancer at events throughout the year and across the country. Information and/or presentations related to **Breast Cancer Deadline 2020**[®] were offered at various conferences in 2011, including the In addition to the strategies related to traditional and online media, NBCC has endeavored to change the conversation in breast cancer at events throughout the year and across the country.

Department of Defense Breast Cancer Research Program Era of Hope meeting, the American Society of Clinical Oncology annual meeting, the San Antonio Breast Cancer Symposium, and meetings organized by the Agency for Healthcare Research & Quality, the ECRI Institute and others. NBCC volunteers also shared information at the Avon Walk in Washington, DC and the EIF Revlon Run/Walk in New York City.

9.5 SUMMARY

In the first full year of the **Breast Cancer Deadline 2020**[®] campaign, NBCC moved quickly to put its plan into action. We have mobilized a collaborative of renowned experts in epidemiology, immunology, clinical care, biotechnology, product development and advocacy to begin work on two key areas: preventing the disease from ever developing; and preventing metastasis, the spread of the disease to other organs, which causes 90%

of breast cancer deaths. We have introduced bipartisan legislation to support our efforts in the US Congress while also building support among public officials. We have educated and mobilized grassroots advocates and organizations to spread the word about **Breast Cancer Deadline 2020**[®] and engage women and men in

the campaign. And, we have reached out to the media and shared information with the general public in order to change the conversation in breast cancer to one that is focused on ending the disease and saving lives.

With less than eight years remaining until January 1, 2020, it is critical that we continue to put forth our most ambitious efforts and pursue them with uncompromised commitment. The goal is achievable with the right amount of passion, leadership and

....it is critical that we continue to put forth our most ambitious efforts and pursue them with uncompromised commitment.

funding. It will require all of us who care to play a role in meeting the goal to find the will, the strength, and the belief to do what it takes to achieve the end of breast cancer. The tools, information, resources and wisdom exist to create a global strategy to end breast cancer.

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