What’s Inside:

NBCC Launches **Breast Cancer Deadline 2020** • A Letter to Breast Cancer Clinicians and Researchers • Tumor Dormancy • Health Care Reform Update • Emerging Leaders Program Develops Young Advocates • 2011 Conference: Changing the Conversation
In 1991, the National Breast Cancer Coalition launched a revolution. We quickly made breast cancer a priority for our government and for our nation. NBCC has again launched a revolution in the battle to end breast cancer with a new weapon—a deadline—Breast Cancer Deadline 2020®. The end of breast cancer by January 1, 2020.

As a network of hundreds of groups and tens of thousands of individuals, NBCC speaks for women. We’re not afraid to rock the boat. We believe scientists must get the funding they need for meaningful breast cancer research. We believe everyone must have access to quality care. We believe trained, educated advocates must have a voice everywhere breast cancer decisions are made.

Our activism has generated more than 2.5 billion new dollars for breast cancer research. Our research initiatives and advocacy helped bring about new models of research, including a significant breakthrough in breast cancer research and care—the first targeted therapy for a particularly aggressive form of breast cancer.

Our vision and advocacy led to the first-ever system of access to care for thousands of low-income women with breast and cervical cancer. And we’ve trained more than 10,000 advocates who challenge the status quo and demand more wherever breast cancer decisions are made—from hospital boardrooms to Capitol Hill.

There was a time when breast cancer was virtually ignored by those with the power to do something about it. Today we are holding these key stakeholders—and ourselves—accountable to Breast Cancer Deadline 2020®, January 1, 2020.
In September we launched our most ambitious initiative yet—
Breast Cancer Deadline 2020®—a deadline to end breast cancer
by January 1, 2020.

We have less than nine years to accomplish this goal. Some say
it’s not achievable. We know it is. But it will take an entirely new
approach to the way we think about, research and talk about breast
cancer. It will take visionaries and risk takers. It will take politicians,
scientists, advocates, service providers, and collaboration with multi-
disciplinary stakeholders to achieve this goal. We can do it. We must
do it.

As you will read throughout this newsletter, NBCC has a plan of
action to change the conversation about breast cancer—and to
change business as usual.

In March of 2010, we began looking at the feasibility of a preventive
vaccine for breast cancer. Some of the leading breast cancer
researchers, as well as a cadre of multi-disciplinary visionaries, are
participating in this work, the Artemis Project. You’ll hear more about
this in the coming months.

Beginning with a baseline report in May 2011, NBCC will issue
annual progress reports about Breast Cancer Deadline 2020®,
summarizing the state of breast cancer as well as the state of our
own work to end breast cancer. We will hold ourselves—and other
key stakeholders—accountable for progress.

We will come together to look at preventing metastasis—making
certain that no more lives are taken. We also will look at preventing
breast cancer from developing in the first place.

This year, we move another year closer to the end of breast cancer
by January 1, 2020. This year we change the conversation and ask
ourselves, “How do we succeed? What must we do differently to
end breast cancer by January 1, 2020?”

Ending breast cancer takes courage, focus, integrity, innovation,
urgency and leadership. NBCC’s decisions and behaviors are
grounded in these values—they guide all our actions.

I hope you will join us in this important strategy to end breast cancer.
It’s the most important action we’ve taken in the 20 years we’ve been
fighting breast cancer.

Sincerely,

Fran Visco
NBCC President
Engaging New Activists

Along with these programmatic efforts, NBCC will undertake an expansive outreach campaign to change the conversation around breast cancer to a dialogue about ending the disease by 2020. Through the use of cutting edge Web tools, social media and advertising, hundreds of thousands of new activists will be engaged to spread the word about Breast Cancer Deadline 2020® worldwide. These women and men will play a role in educating their communities about how to end breast cancer.

The work outlined above will lay the foundation for NBCC’s work on Breast Cancer Deadline 2020®. NBCC will continue to supplement these activities with our ongoing efforts in advocacy, training and quality care.

Join the Breast Cancer Deadline 2020® Movement

NBCC challenges you to become educated, speak up on behalf of women and men everywhere and take action to end this disease. We also call on you to spread this message to anyone you know who cares about ending breast cancer. We will give you the tools and opportunities to get involved and make a difference. You can also help spread the word by visiting BreastCancerDeadline2020.org. We urge you to donate what you can on our website so that we can convene stakeholders, catalyze progress and engage more people worldwide.

A deadline changes everything and makes the impossible possible. The unimaginable becomes reality with a deadline, strong leadership and strategic vision. The deadline is a lifeline for all of us who care about breast cancer. The end of breast cancer by January 1, 2020. This is real.

Are You With Us?

Actions You Can Take to Advance Breast Cancer Deadline 2020®

NBCC’s brand of advocacy requires real grassroots involvement and work at both the community level and the national level to produce change for everyone. Our mission to end breast cancer by January 1, 2020 calls for grassroots advocates working with individuals, groups and the general public in their local community and with your state congressional delegations to expand support for our work. Here are some actions you can take at home that have immediate impact:

- Spread the Word About Breast Cancer Deadline 2020® in Your Community
  There are numerous individuals and groups who care about breast cancer at the community level but don’t yet know about Breast Cancer Deadline 2020®. These individuals need to be identified, engaged, educated and encouraged to get involved. On the ground, advocates helping to do the hard work of reaching out to individuals and community groups are invaluable to our efforts to spread the word and expand our support network. NBCC has created tools and information that can assist our grassroots supporters to bring Breast Cancer Deadline 2020® efforts to the community. Visit BreastCancerDeadline2020.org to get involved.
- Showcase Breast Cancer Deadline 2020® at Community Events
  Research local health fairs, community events and/or other opportunities where you can volunteer to staff an NBCC table to distribute information and materials about Breast Cancer Deadline 2020®. Contact Kathryn Johnson at 202.973.0879 or KJohnson@BreastCancerDeadline2020.org about events coming up in your community that provide good opportunities for outreach, and we will work with you to supply the tools for distribution.
- Contact your Senators and Representatives to Urge Them to Support Breast Cancer Deadline 2020®
  The NBCC Action Center, BreastCancerDeadline2020.org/ActionCenter, has tools to assist you in sending a message to your Representative and Senators that says you support Breast Cancer Deadline 2020® and are calling on Congress to support it too.
- Most Importantly, Register for NBCC’s 2011 Annual Advocacy Training Conference
  And encourage other interested advocates from your community to do the same. Many of the conference plenaries and workshops will focus on Breast Cancer Deadline 2020®, and the conference provides a wonderful opportunity to ask questions, learn more about the specifics and network with others about strategies to support the overall goal. Register today at BreastCancerDeadline2020.org/2011Conference.
- Participate in the Annual Lobby Day Following the Conference
  The 112th Congress has 16 new Senators and 96 new members in the House of Representatives. They and the returning members will need to be educated about Breast Cancer Deadline 2020® and what they can do to support it. How do we convince them? A critically important action is to show them how many of their constituents support Breast Cancer Deadline 2020®. Register today at BreastCancerDeadline2020.org/2011Conference.

A Strategy for Capitol Hill

With the convening of the 112th United States Congress, NBCC is amplifying its efforts and incorporating some new tools to spread its message about the urgency of Breast Cancer Deadline 2020® to both old and new members of Congress.

As a result of the November 2010 elections, the Republicans gained control of the House of Representatives, while Democrats retain a majority in the Senate. The House adds 98 newcomers to its ranks, while the Senate brings in 16 new members.

The new session of Congress brings a great opportunity for NBCC to reach out to the new legislators and leaders in the House and Senate and introduce them to the Coalition, educate them about breast cancer and discuss the role they can play in helping us reach Breast Cancer Deadline 2020®.

Our Strategy will Include:
- Congressional Forums to educate about breast cancer, NBCC and Breast Cancer Deadline 2020®
- Legislation to support Breast Cancer Deadline 2020®
- Ongoing material and meetings for Congress and the Administration;
- Targeted lobby days throughout the year.

What Can You Do to Help?
Visit our Action Center for regular updates on what you can do to promote NBCC’s legislative initiatives or call The Legislative Hotline at 1.888.973.NBCC (6222).
We made our mark in the latter half of 2010 with news items on topics including “peeling back the pink,” to “changing the conversation,” honoring advocates at our annual gala and responding to the end-of-the-year FDA ruling on Avastin.


In October, NBCC appeared in blogs, top-tier newspapers and television interviews featuring NBCC and Fran Visco. The Los Angeles Times pointed out “The Down Side of Awareness Campaigns®” in an October 4 article quoting Visco on the lack of progress made towards eradicating the disease.

Visco made an even further push in an October 4 Huffington Post editorial piece, “Why I’m Not Celebrating Breast Cancer Awareness Month.”

In an October 7 MSNBC interview with Tom Roberts, Visco shared her thoughts about the pinking of America during the month of October as she reflected on her Huffington Post article.

NBCC challenged readers to change the conversation through Visco’s November 4 Huffington Post piece, “It’s November; Time to Talk About Elections, Turkey and Breast Cancer?”


In December, the news focused on the FDA’s decision to revoke Avastin’s approval for breast cancer treatment. Visco was quoted in the Washington Post, and NBCC’s statement on the Avastin ruling was picked up by The New York Times (December 17, 2010). Breast Cancer Deadline 2020® also made the news on December 9, when WUSA-9 Washington, DC area CBS reporter Andrea Roane broadcast an interview with Visco.


NBCC’s long-standing relationship with President Bill Clinton started in the early ’90s when we urged the Clinton Administration to create a National Action Plan on Breast Cancer, an innovative collaboration of government, science, private industry and consumers. President Clinton established the group and asked NBCC President Fran Visco to co-chair the Plan’s implementation. We worked with his administration to guarantee access to treatment for underserved women whose breast cancers were found through government funded programs and to ensure a high level of funding for innovative breast cancer research. In 2005, together, NBCC and President Clinton launched the Virginia Clinton Kelley Fund at NBCC to honor the memory of President Clinton’s mother. Today, President Clinton supports NBCC’s Breast Cancer Deadline 2020®. In a video featuring President Clinton, he shares his appreciation saying, “I applaud the National Breast Cancer Coalition’s courage to launch this ambitious campaign to end breast cancer by 2020. The stakes are too high, the losses have been too great to let another decade go by…. And if I know anyone who can do this, it’s you.” To see the full video, go to BreastCancerDeadline2020.org, and click on “Hear What the Leaders Say.”
On December 16, 2010, the Food and Drug Administration (FDA) announced it was beginning the process of removing breast cancer as an indication for the drug Avastin because the drug has not been shown to be safe and effective for that use. The FDA made this decision after reviewing the results of four clinical studies of Avastin in breast cancer that show no improvement in overall survival and insufficient benefit in slowing disease progression to outweigh the significant risks to patients. The risks include severe high blood pressure; bleeding and hemorrhage; the development of perforations (or “holes”) in the body, including in the nose, stomach, and intestines; and an increased risk of heart failure. The following is NBCC’s statement in support of the FDA’s decision.

**NBCC Supports Withdrawing FDA Approval of Avastin for Breast Cancer**

**Anti-Angiogenesis Therapy: Another Once Promising Avenue of Breast Cancer Treatment Disappoints**

In May of 1998, a front page story in The New York Times reported on a new approach to cancer that then head of the National Cancer Institute called “the single most exciting thing on the horizon” for cancer ("Hope in the Lab: A special report; A cautious awe greets drugs that eradicate tumors in mice," by Gina Kolata, May 3, 1998). Others said they were "electrified” when they heard the results of mouse studies of this new drug based on the theory of anti-angiogenesis. A noble laureate was quoted as saying that the scientist behind the theory “is going to cure cancer in two years.” As is too often the case in cancer, the hype did not become the reality. The story of the cancer community’s hope for anti-angiogenesis approaches, the work that went into the development of the first drug to reach clinical trials, and the sobering reality of its lack of effectiveness are all important for advocates to know and understand.

There was much excitement in the breast cancer community when the first anti-angiogenic drug was moved into clinical trials. NBCC certainly shared that excitement and looked forward to working with scientists and industry to develop the clinical trials necessary to prove that the drugs were effective. As Jerome Groopman said in that The New York Times’s article in 1998: "We are all driven by hope...but a sober scientist waits for the data.” As does an educated advocate.

### The Story of Avastin

Angiogenesis is the growth of blood vessels. Judah Folkman’s theory was that if we could stop the growth of blood vessels, which bring vital nutrients to tumors, we could stop tumor growth and save lives. His work ultimately led to the development of bevacizumab—the brand name Avastin. This was the first anti-angiogenesis drug to be marketed for cancer treatment and was approved by the FDA in 2004 for the first-line treatment of metastatic cancer of the colon or rectum (colorectal cancer) in combination with 5-fluouracil (5-FU)-based chemotherapy. Avastin was approved for colorectal cancer based on a randomized clinical trial that demonstrated an improvement of approximately five months in overall survival. However, within six months of approval, the FDA and the drug maker Genentech began to issue drug warnings about Avastin. On August 12, 2004, a warning was issued to health care providers that there is evidence of an increased risk of serious adverse gastrointestinal fistula formation, including colorectal, rectal, and angina related to Avastin.

On September 27, 2006, another warning was issued to health care providers that, for patients taking Avastin, there is evidence of an increased risk of reversible, posterior leukoencephalopathy syndrome (RPLS), a rare brain-capillary leak syndrome associated with hypertension, fluid retention, and cytotoxic effects of drugs.

On September 24, 2007, the FDA issued a safety labeling update. The update presents new data that non-gastrointestinal fistula formation has been reported in patients treated with Avastin in controlled clinical studies and in post-marketing experience, in some cases causing death.

### Avastin for Breast Cancer

Back in 2000, the idea that this new approach could have a significant impact on breast cancer, and could save lives, was exciting. NBCC was eager to work with scientists and industry to prove the drugs were effective, and collaborated with Genentech on a Phase III clinical trial of Avastin for the treatment of metastatic breast cancer. NBCC’s involvement in the trial reflected the patient-centered values and criteria outlined in NBCC’s Clinical Trials Initiative, established two years earlier. If the study is asking a novel question that is important to patients, NBCC works to link trial investigators with the design and oversight of the trial. These partnerships include advising on protocol development, participating on trial steering committees, monitoring and supporting the work of data safety monitoring boards, and assisting with outreach and accrual of patients.

NBCC felt the Avastin trial was asking an important and novel question—would the drug, in combination with Xeloda (capecitabine), help women with metastatic breast cancer live longer?

### Disappointment

When Genentech announced the final analysis of the trial in 2002, NBCC was disappointed to learn that Avastin had not increased progression-free survival (time to disease progression) or overall survival for women with relapsed metastatic breast cancer. But NBCC and investigators continued to be hopeful that treatment of less advanced tumors might yield more promising results. Another trial, E2100, had just begun enrolling to look at Avastin in the first line treatment of metastatic breast cancer, in combination with Taxol (paclitaxel).

### Continued Disappointment

Hundreds of clinical trials have since been launched to test the theory that anti-angiogenesis would slow breast cancer growth and save lives in patients with different types and stages of cancer. But unfortunately, in each of the trials that have been completed so far, we have seen evidence that the drug is not safe and effective for the majority of breast cancer patients. The studies have consistently shown that women who are taking the drug are not living longer, and are in fact at an increased risk of dying from adverse side effects. A recent analysis published in the Journal of Clinical Oncology found that Avastin “is associated with an increased risk for significant heart failure in patients with breast cancer.”

### No Increase in Survival for Breast Cancer Patients

But Increase in Harm

In 2008, the FDA made the controversial decision to grant accelerated approval of Avastin for metastatic breast cancer based on the AVADO trial (angiogenesis in breast cancer: evaluating treatment outcomes and drug effectiveness) in 2007. This was a randomized clinical trial that demonstrated an improvement of 5 months for women in the taxane and anthracycline groups and 2.9 months for women in the capecitabine group. Together, the studies enrolled almost 2,500 women.

Neither study showed an improvement in overall survival with the addition of Avastin, but in fact, an increased risk of death. An FDA analysis of the data showed that 0.8% of the women in AVADO and 1.2% of the women in RIBBON 1 who received Avastin died from side effects thought to be related to the drug.

On December 16, 2010, the FDA announced it would follow the ODAC recommendation and it began the process for withdrawing the breast cancer indication from bevacizumab drug approval.

### Looking Ahead

Based on the results of randomized clinical trials showing no increased survival benefit from Avastin but increase in harm, NBCC supports the FDA decision. NBCC has set January 1, 2020 as a deadline for ending breast cancer, and the FDA’s action is one small step in the right direction. We will not meet our deadline if significant research and health care interventions, and treatments that will have a significant and meaningful impact for women.

Together, we must focus advocacy, public policy and resources on saving lives, doing more good than harm, and ultimately ending this disease by January 1, 2020.

In September, the National Breast Cancer Coalition (NBCC) declared a deadline to end breast cancer—January 1, 2020. Ending breast cancer is not a new idea for us. Our mission for almost 20 years has been the eradication of breast cancer. Over the past two decades we successfully fought for increased federal funding for the scientific community, collaborated with researchers to move ideas forward and launched new models for training advocates in research methodology and science. Working together with you, we made a difference.

We appreciate the scientific progress that has been made during this time. We know much more about the biology of breast cancer, and strides have been made in many areas of technology such as genomics and nanotechnology that could impact diagnosis and treatment of disease. We have moved toward a world of targeted, less toxic treatments.

And yet, with all of this, progress in the clinic has been incremental. The advances in knowledge and new scientific tools have not been translated quickly, if at all, into progress for women with or at risk for breast cancer.

We’ve listened to scientists and clinicians over the years who share our frustrations. They have told us that they too are dissatisfied with the status quo, that the current system of research often stymies innovation. They are impatient with the bureaucracy of funding and clinical trials that allows so many bench discoveries to languish before ever making it to the clinic, or prevents new ideas from ever being funded.

We asked what we could do to change the system. We have already brought billions of new dollars to science, fostered a new appreciation within the public for research and created innovative collaborations between advocates and scientists. How do we harness the significant discoveries that have already been made and help facilitate the work of those who are dedicated to doing innovative and clinically meaningful research? How do we shift the focus of resources, institutions and scientists to the work that will have the most impact on ending this disease?

After much thought and debate, we chose to set a deadline. We know that setting a deadline alone won’t end breast cancer, but we believe a change in focus will. Setting the deadline is a tool to change the focus over the next ten years; to change how all of us view our work in breast cancer and how we do it. To bring back a sense of urgency to breast cancer. Business as usual is not working for women. And very often we hear that it is not working for you. A deadline will help us all reset the course.

But we haven’t just set a deadline; we have also developed a strategic plan to engage all of the stakeholders around it. Scientists, regulators, industry representatives, advocates and all who care have been and will continue to be involved in the plan. This includes meetings focused on specific areas that will be crucial to achieving the deadline. The emphasis is on removing barriers and encouraging collaboration, and shifting the focus away from publications, patents and drug development to interventions that can have a dramatic impact for women.

We invite you to join us. Be a part of this, even if you are skeptical. We need your skepticism to help us identify the barriers to achieving the end of breast cancer and your help in overcoming them.

NBCC advocates believe we will eradicate breast cancer by focusing and aggregating efforts in two key areas: learning how to stop breast cancer metastasis from taking women’s lives and learning how to prevent the disease from developing. Both of these strategies will require innovations in the system to allow high-quality scientific evaluation of new interventions in a rapid manner.

NBCC will be hosting strategic summits, catalytic workshops and collaborative efforts with a multi-disciplinary and diverse group of stakeholders to focus on these key areas. A summit on metastasis is being planned for August 2011, and a summit on prevention is planned for October 2011. The goal of these summits is to identify the most promising areas of research, those areas which could have a significant impact on the incidence or mortality of the disease in the context of the deadline. Catalytic workshops will be held around the most promising areas of research in 2012 and beyond. The activities and progress will be tracked and summarized in annual reports issued by NBCC.

NBCC has already begun to hold a series of catalytic workshops on the development of a prophylactic breast cancer vaccine. As a result, the Artemis Project has been launched to develop and implement a five-year strategic plan for a preventive vaccine. This project is being led by advocates and includes several researchers from different institutions including Cold Spring Harbor Laboratory, Duke Comprehensive Cancer Center, City of Hope Beckman Research Institute, University of California Los Angeles, and the Stanford University School of Medicine, among others.

Imagine, just for a moment, that we all collaborated and that we met the deadline. How do you envision that we got there? What barriers did we remove? What did we change? We want to hear from you.

We can keep on doing what we are doing, and I think we can guess where we will be on January 1, 2020. Or we can declare a deadline and bring back that sense of urgency and the catalyst we need for change. We chose to declare a deadline. Are you with us?
Breast Cancer Research in 2010 and the Breast Cancer Deadline 2020®

By Guest Blogger, Laura Nikolaides
December 13, 2010

Cure invited Laura Nikolaides, director of research & quality care programs at the National Breast Cancer Coalition, to share her thoughts on the 2010 meeting of the San Antonio Breast Cancer Symposium and NBCC’s Breast Cancer Deadline 2020®.

One year I want to return home from the San Antonio Breast Cancer Symposium (SABCS) with great news for my daughter Kira, who is 11. I want to tell her that there were big new discoveries, and she won’t need to worry about having breast cancer or going through the harsh treatments that her mom did.

But leaving this year’s meeting, the 33rd, I think about what I can tell her. We may have some new combinations of drug treatment or some new schedules that are just as good as the old ones or maybe a little better. We found out that several drugs don’t work like we thought they would. We may have some new options for treatment that will be less toxic. But I cannot tell her that we are any closer to knowing how to prevent or stop metastasis of the disease from taking women’s lives, the things that will matter most for her generation. If we change the focus of the extensive resources devoted to breast cancer research now, we will meet our Breast Cancer Deadline 2020®, which will be great news for Kira and her friends.

Go to CureToday.com to read Laura’s full report.

Learn the Facts.
Know the Evidence.
Become an Advocate.

You hear a lot of messages about breast cancer. But how do you know what is true?

KnowBreastCancer.org gives you the facts behind the major issues in breast cancer so you can decide for yourself. Be empowered by becoming informed.

Tumor Dormancy—What is it? Why Does it Happen? Can it be Targeted to Meet Breast Cancer Deadline 2020®?

After treatment for cancer, some tumors will reappear to grow and spread, sometimes several years later. The period of time before the tumor resurfaces is called tumor dormancy. Tumor dormancy is more likely to be observed with certain types of cancer, including breast cancer. In fact, breast cancer has been known to reappear up to 25 years after initial treatment (Stephens, 1996).

One aspect to ending breast cancer by 2020 will be in understanding how and why breast cancer tumor dormancy occurs. Greater knowledge could lead to learning how to wipe out any lingering cancer cells or learning how to keep them dormant permanently. Unfortunately, tumor dormancy is currently poorly understood.

While tumor dormancy is not a commonly studied topic, a few researchers are focusing their efforts on the subject. In a session entitled “Breast Cancer Recurrence and Tumor Dormancy, the things that will matter most for her generation” at the 2010 San Antonio Breast Cancer Symposium, presenters Patricia Steeg, PhD, of the National Cancer Institute, and Lewis A. Chodosh, MD, PhD, of the University of Pennsylvania School of Medicine both concluded with a resounding, “Yes, tumor dormancy does matter.” All breast cancer survivors are at risk of dying from the disease because of tumor dormancy and recurrence. Tumor dormancy is the critical determination of clinical outcome, they said.

Unfortunately, both researchers said we still have more questions than answers. How common is tumor dormancy? Where do the dormant cells reside in the body? What reawakens them? We don’t yet know the answers to these questions, according to Drs. Steeg and Chodosh. According to these researchers, it appears that dormant cells are looking more like cancer stem cells, a small subset of tumor cells that are thought to have the ability to renew themselves.

One of the barriers to this research has been the lack of preclinical models for studying tumor dormancy. Most of the previous metastasis research has used models that provide results within a short time frame. Cell lines used to study metastasis have also been selected because of their rapid metastatic ability, not because of any ability to lie dormant for a time period. Pushing efforts forward for more understanding of tumor dormancy will first require the development of models that can be used for research.

A barrier to research in humans—the difficulty in detecting circulating or disseminated tumor cells in the body—has recently been reduced with advances in technology. Evolving advances are allowing researchers to now detect tumor cells in the blood and bone marrow in women with no evidence of disease. Circulating breast cancer cells have now been detected in women without evidence of disease up to 22 years after diagnosis (Goss, 2010). But much, much work still needs to be done to understand whether these cells represent a pool of dormant cells that can and will reinitiate growth and if there are signals in the microenvironment or surrounding area of the cells that cause this reawakening of cancer growth, and ultimately what to do to prevent it. We do not want to end up with research that is focused on targeting circulating breast cancer cells that most of us have and that would never become a problem.

To meet Breast Cancer Deadline 2020®, it is crucial that we as advocates convey urgency to the scientific community about answering these critical questions.


Why Health Care Reform Matters to Breast Cancer Survivors

New Protections under the Law—The Affordable Care Act (ACA)

No Pre-Existing Conditions—Beginning in 2014, group health plans and new individual plans will no longer be able to exclude you from coverage or charge you a higher premium if you have a pre-existing condition.

Lifetime and Annual Caps—Health insurance plans are prohibited from imposing annual or lifetime caps on benefits, and the use of annual dollar limits after September 23, 2010 is restricted. Beginning in 2014, annual limits also will be banned.

No Rescission—Insurers cannot cancel your insurance policy when you need it most.

No Discrimination—No longer will insurance plans be allowed to charge you more simply because of your gender or your health status, where you live, or if you are participating in a clinical trial.

Other Protections—Access to internal and external appeals processes (2011); the right to designate or retain your primary care provider (2014); access to clear and standardized information about insurance options through a new web portal as well as through state-based health care consumer assistance programs.

Access to New Health Insurance Options

Pre-Existing Condition Insurance Plan (PCIP)—If you have been denied coverage due to a pre-existing condition such as breast cancer, you may be eligible to enroll in the newly created, temporary insurance pools in every state between now and 2013. Beginning in 2014, group health plans and new individual plans will no longer be able to exclude you from coverage or charge you a higher premium if you have a pre-existing condition.

State-Based Health Insurance Exchanges Provide Coverage that is More Affordable—In 2014, there will be a transition to a new health insurance marketplace where a range of health insurance options will become available for individuals and small businesses. The establishment of state-based health insurance exchanges will enable people to shop for standardized health insurance packages, and low income individuals and families will have access to subsidies to help defray the cost of coverage.

Medicaid Eligibility for Childless Adults—States are now allowed to begin expanding Medicaid eligibility to nonelderly individuals at 133 percent of poverty or below. All states will be required to offer coverage by 2014.

Patients and Consumers Have a Voice in the Process

Under the law, educated health care consumers will have an opportunity to play a role in a range of decision-making bodies implementing health care reform.

Improvement in Quality of Care and Patient Outcomes

The law supports a variety of approaches to research and analysis that will enhance the process, type and quality of care delivered as well as improve overall patient health and outcomes. This research will help to determine the most effective and appropriate treatments and systems of care for women and men with breast cancer through the Patient Centered Outcomes Research Institute.

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Role for Educated Breast Cancer Advocates Never Greater

By Nancy Ryan, NBCC Advocate

The National Breast Cancer Coalition’s new initiative, Breast Cancer Deadline 2020®, motivated me to attend the 33rd Annual San Antonio Breast Cancer Symposium (SABCS), December 8-12, 2010. Breast Cancer Deadline 2020® aims to harness our breast cancer resources and focus them on ending this disease by January 2020. Since SABCS is the largest gathering of breast cancer researchers, scientists, clinicians and advocates in the world, I decided to learn first-hand about the latest in breast cancer research.

I have attended every National Breast Cancer Coalition Advocacy Conference since NBCC’s inception; graduated in 2004 from Project LEAD, NBCC’s science training for advocates; and went to SABCS in 2005. Still, I was overwhelmed by the quantity, intensity and complexity of the science presented at this meeting. Other advocates shared my impression that much of the research involved testing new combinations of treatments or drugs for various types and subtypes of breast cancer (e.g., ER/PR status, HER2 status) and when to give them to patients—in the neoadjuvant setting (before surgery) or after, sequentially or in combination. In other words, “tweaking” treatment in small increments. We heard little at this meeting that will change clinical practice. Many presentations ended with more questions than answers.

Several advocates have written excellent summaries of the science presented at this meeting. Musa Mayer’s report for the American Association for Cancer Research’s CR Magazine, “SABCS ROUND-UP: An Overwhelming Sense of Urgency,” can be found at: CRMagazine.org.

Did the work presented at this year’s SABCS move us towards our Breast Cancer Deadline 2020® goal? In this advocate’s opinion, perhaps, but not fast enough. Most advocates at the meeting shared my frustration about the slow pace of breast cancer research. Very little research funding goes into breast cancer prevention. The process of metastasis is poorly understood. According to one presenter, Dr. George Sledge, the database of genetic information (once heralded as the key to ending cancer) is becoming so large, it may soon outpace our ability to store, manage, and use it effectively to treat and cure patients. Drug resistance and drug expense are major hurdles. Clinical trial accrual rates are low. We don’t need to tweak current treatments. We need to address these larger problems, and we need to do it quickly.

I did experience several bright moments at the symposium. I spoke with several scientists about NBCC’s Breast Cancer Deadline 2020®. Each one was skeptical at first. But after stating our rationale for establishing the deadline and reminding them 40,000 U.S. women still die every year from breast cancer, they all agreed with the challenges we face. I felt I successfully conveyed our sense of urgency. I was heartened to encounter scientists poring over their work and sharing ideas in between sessions—during breaks, lunchtime and even on the plane ride home. The symposium teased me with tempting ideas for future research such as defining the role of circulating tumor cells, understanding cancer cell dormancy and clarifying the role of biomarkers. By next year, we need to make sure researchers are investigating the issues that will carry us to our Breast Cancer Deadline 2020® goal.

If we are to meet Breast Cancer Deadline 2020®, the role for advocates is critical. We need to probe the research community with tough questions and offer to help answer them. What are the obstacles to accelerating the scientific process? How many studies do we really need on one drug? How can we encourage greater collaboration among investigators and institutions? Is the current system optimized for complete response to a drug before surgery important if it does not affect long-term survival? What can we learn from long-term survivors that may lead to brand new research questions? How can we steer research towards prevention and metastasis?

As we move forward with Breast Cancer Deadline 2020®, all advocates should follow the implementation of the National Breast Cancer Coalition’s Annual Advocacy Training Conference scheduled for April 30-May 3, 2011, and next year’s San Antonio Breast Cancer Symposium from December 6-10, 2011. The role for educated breast cancer advocates has never been greater.

Monthly Giving Society

Want to make your dollar count all year? Enjoy the convenience of uninterrupted membership, without the bother of renewal reminders from us.

To sign up, visit BreastCancerDeadline2020.org/Join or contact Leslie Chadwell at 202.973.0569 or Donations@BreastCancerDeadline2020.org.

Host a Community Event

Whether it’s a wedding, anniversary, graduation or birthday, or you simply want to encourage others to take action, the funds that you raise will support Breast Cancer Deadline 2020®.

Visit BreastCancerDeadline2020.org/Fundraising to learn more. Contact Leslie Chadwell at 202.973.0569 or LChadwell@BreastCancerDeadline2020.org.

UPDATE: Health Care Reform Implementation

As the one year anniversary of the passage of the health care reform law approaches, NBCC continues its efforts to inform both policy makers and individuals across the nation why the law is so important for breast cancer survivors. We continue to closely follow the implementation of the law and the challenges it faces.

In August 2010, NBCC held a webinar led by NBCC President Fran Visco titled, “What Does Health Care Reform Implementation Mean for Breast Cancer Survivors?” as part of our effort to educate the public about the new law. The webinar, available at BreastCancerDeadline2020.org/ActionCenter, explains many of the new protections and insurance options under the law that are significant for breast cancer survivors, including those which have already taken effect.

As implementation of the health care reform law continues, so do the efforts to challenge and repeal it. So far, nearly two dozen legal challenges have been posed to the law. At press time, a judge in the lawsuit filed by the Virginia Attorney General found the provision of the law requiring individuals to purchase insurance, commonly referred to as the “individual mandate,” to be unconstitutional, becoming the first court in the country to invalidate any part of the law. The judge in this case, however, declined the Attorney General’s request to freeze implementation of the law pending appeal. In February, a judge in a significant multi-state lawsuit in the Northern District of Florida ruled the entire law unconstitutional, but also allowed implementation of the law to move forward pending future legal action. Due to the current contradictory verdicts it is widely expected the issue will ultimately be decided by the U.S. Supreme Court.

Legislatively, on January 19, the House of Representatives voted in favor of repealing the law, while an attempt by the Senate failed in February. Other tactics, such as denying funding necessary for the government to successfully implement portions of the law through the appropriations process or attempting to repeal individual portions are likely to continue.
Emerging Leaders Program Develops Confident, Connected Young Advocates

Confident. Connected. Open to Change. These are among the defining characteristics of the Millennial Generation (ages 18-35) who are well-versed in NBCC’s evidence-based approach to science and research, and have participated in NBCC’s training programs and systems-change advocacy efforts. Confident to our goals and priorities, and currently a member of NBCC, these young adults are helping end breast cancer as they move into significant positions of leadership within NBCC.

Emerging Leaders College Initiative

NBCC’s Emerging Leaders College Initiative, a successful program with colleges, is on track to expand dramatically this spring. The program, designed to enable students to integrate academic credit, course studies, and the hands-on experience of attending NBCC’s Advocacy Training Conference and Lobby Day, has been honored by Professor Jessica Henderson and her students at Western Oregon University. Attend the workshop at the 2011 Advocacy Training Conference, where Professor Henderson presents this model, and learn more about developing a similar program in your college setting.

Emerging Leaders College Ambassadors

Also on the horizon, a new program, Emerging Leaders College Ambassadors, offers students internship credit for serving as “NBCC Ambassadors” on their college campuses. Trained and supported by NBCC, the students in this program carry out their internship on their campus. Acting as an ambassador, the students perform outreach initiatives such as disseminating information on behalf of NBCC, organizing students for NBCC events, and serving an interest in the Advocacy Training Conference and other NBCC education and training opportunities.

For Breast Cancer Deadline 2020* to succeed, activists of all ages must play their part. For more information, visit BreastCancerDeadline2020.org/EmergingLeaders or contact Kathryn Johnson at KJohnson@BreastCancerDeadline2020.org or 202.973.0579.

The Center for NBCC Advocacy Training

The year 2011 promises to be full of excitement for the Center for NBCC Advocacy Training. This centralized home for our education and training programs teaches breast cancer activists the public policy and research-focused approach to advocacy that NBCC has pioneered. The Center’s exciting programming for 2011 features offerings (see below) for advocates at all skill levels, which gives participants the necessary tools needed to play a part in scientific and policy decision-making around critical issues in breast cancer.

Project LEAD Workshops

From January 7-9, the Center for NBCC Advocacy Training hosted a Project LEAD workshop in Tampa, FL. A second workshop will be held this October in Seattle, WA. These 2-day training programs focus on providing advocates an introductory education on the evidence base of breast cancer. LEAD workshop students study the biological concepts underlying breast cancer and the research methods used to gather new evidence. They also develop skills and learn the evidence-basis criteria needed to critically review how the media reports the science of breast cancer. Graduates of these workshops seeking more training in research advocacy can then apply to the Center’s more advanced Project LEAD Institute.

International Project LEAD

International Project LEAD was developed to teach breast cancer advocates the language and concepts of the science of breast cancer and the importance of clinical trials from a global perspective. It brings together advocates from around the world to develop their ability to critically read scientific information, ask important questions and effectively educate their communities about the importance of evidence and research. NBCC offered its fourth International Project LEAD course from February 2-5, 2011 in Cancun, Mexico. The course was taught by internationally-renowned scientists with a combination of the basic Project LEAD curriculum and a special emphasis on clinical trials, ethics, regulation and safety issues relevant to an international audience. Additionally, the program focused on the challenges and opportunities presented by international advocate participation in and collaboration on breast cancer research.

Annual Advocacy Training Conference

This year’s Annual Advocacy Training Conference, to be held at the Hyatt Regency Crystal City in Arlington, VA (minutes from Washington, DC), promises to be groundbreaking as we aim to start Changing the Conversation about breast cancer. With a focus on Breast Cancer Deadline 2020*, we believe the science must answer critical questions about prevention and stopping metastasis. Hope and pink ribbons won’t win the battles, but striving towards the objective of a deadline with an action plan in hand will bring us closer to our goal. Read more about the conference on pages 18-19.

Project LEAD Institute

The 2011 Project LEAD Institute will be held July 17-22 in San Diego, CA. The Institute will offer participants a 6-day intensive study of cancer biology, genetics, epidemiology, research design and advocacy. Participants also attend advanced breast cancer topic sessions and research seminars and clarify their learning in small study groups guided by faculty. They learn to distinguish between descriptive studies, analytic studies, clinical trials, and meta-analyses and identify the extent to which each establishes causality. Guided by veteran advocate mentors, Institute graduates go on to participate in the wide range of consumer advocacy opportunities available and bring their influence to the breast cancer research decision-making process.

Project LEAD Advanced Topics at the San Antonio Breast Cancer Symposium

The San Antonio Breast Cancer Symposium, the world’s largest conference on breast cancer, will be the site this December 2011 of an annual National Breast Cancer Advocacy LEADcast session presented by a provocative speaker on a significant research topic, followed by an advocate-led panel on cutting edge research from the advocate perspective.

Continuing Education LEADcasts


Schedule for 2011

The Center for NBCC Advocacy Training will continue with its robust selection of advocate training programs in 2011. We look forward to seeing you at our programs and courses! For more information, visit BreastCancerDeadline2020.org/LEADcast.

January 7 - 9 Project LEAD Workshop, Tampa, FL

February 2 - 5 International LEAD, Cancun, Mexico

March LEADcast

April 30 – May 3 NBCC’s Annual Advocacy Training Conference, Washington, DC

June LEADcast

July 17-21 Project LEAD Institute, San Diego, CA

October Project LEAD Workshop, Seattle, WA; LEADcast

December Project LEAD Advanced Topics; San Antonio Breast Cancer Symposium

BreastCancerDeadline2020.org

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National Breast Cancer Coalition has set a deadline to end breast cancer. Join us at NBCC’s 2011 Annual Advocacy Training Conference to find out how you can be an integral part of Breast Cancer Deadline 2020®.

For decades, the breast cancer movement has existed within the context of hoping to find a cure and hoping for an end. NBCC says, “No more.” By setting a deadline we demand that from this moment forward, all research and policy decisions surrounding breast cancer are made and guided by the goal of ending this disease by 2020.

NBCC’s 2011 Annual Advocacy Training Conference will teach breast cancer advocates how they can play a vital role in shifting the conversation to a focus on ending breast cancer by 2020. Sessions will give advocates the skills, knowledge and tools they need to support Breast Cancer Deadline 2020® both locally and nationally.

The 2011 conference program will provide advocates access to:
• Experts in innovation with proven track records for directing successful change initiatives;
• Leading scientists in key areas of prevention and metastasis;
• Front-line policy makers discussing how to change government to help achieve the Breast Cancer Deadline 2020® goal;
• Hands-on training on the most effective advocacy strategies to end breast cancer.

Join the conversation at NBCC’s 2011 Annual Advocacy Training Conference in Washington, DC and be part of the movement that ends breast cancer by 2020.
On October 4, 2010, we welcomed more than 250 guests to the Tawdry 10th Anniversary Les Girls cabaret at the Avalon Hollywood in Los Angeles. The evening included a cocktail hour featuring a silent auction and celebrity-filled cabaret. Once again, it was a fantastic show with incredible talent. We were successful in accomplishing our goal of raising funds for NBCC and honored Arleen Sorkin (pictured above, right, with Alec Call, Fran Visco and Bryan Johns) for her work on our behalf.

Performers included Julie Bowen (pictured above, center, with Ty Burrell), Wayne Brady, Ty Burrell, Jesse Tyler Ferguson, and honored Arleen Sorkin (pictured above, right, with Alec Call, Fran Visco and Bryan Johns) for her work on our behalf.

On behalf of all of us at the National Breast Cancer Coalition, and the 3 million women and men living with breast cancer in the United States today, thank you to our partners and those of you who support them. With your help, we can do this. We can bring an end to breast cancer by 2020.

If you would like to partner with NBCC on a cause related marketing promotion, contact Leslie Chadwell at 202.973.0569 or LChadwell@BreastCancerDeadline2020.org.

## Cause Marketing Partners

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**Les Girls 10 Honors Arleen Sorkin**

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Performers included Julie Bowen (pictured above, center, with Ty Burrell), Wayne Brady, Ty Burrell, Jesse Tyler Ferguson, Chris Gorham, Samantha Harris, Sharon Lawrence, Jenifer Lewis, Busy Philipps (pictured above, left), Cynthia Sikes, Eric Stonestreet, Steven Weber and Rutina Wesley.

**2010 New York Gala Honors Debra Lee and Fern Mallis**

On Tuesday, November 9, NBCC recognized four outstanding individuals for their work to help end breast cancer at the 15th Annual New York Gala, held at Cipriani 42nd Street.

This year’s honorees were Fern Mallis, President of Fern Mallis, LLC (pictured above, left with Fran Visco) and Debra Lee, Chairman and CEO of BET Networks (pictured above, right with advocate Samantha Reed), who each received NBCC’s Wo-men Who Get It Right® Advocacy Award, for their tremendous contributions and ongoing efforts to end breast cancer.

Our grassroots advocates, Linda Cady and Timolin Jefferson of Georgia (pictured above, center/right), embody the spirit of NBCC: passionate, relentless and mission-driven, and each received a 2010 Grassroots Advocacy Award. We were delighted to recognize them for their leadership and the extraordinary work they have done.

The evening was made possible by the leadership of the incredible New York Gala co-chairs; Alan T. Ennis, President and CEO, Revlon (pictured above, center/left); Sumner M. Redstone, Chairman, CBS Corporation, Viacom, and Daniella Vitale, Chief Merchant and Executive Vice President, Barneys New York.

Award-winning musical artist LaChante was the evening’s musical performer.

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**Why I Support Breast Cancer Deadline 2020**

NBCC is proud of the generosity of its donors across the country who support our vital work. Whether they are involved for personal reasons or they’ve been touched by breast cancer through a loved one, they support NBCC’s Breast Cancer Deadline 2020® for one reason—to end breast cancer by January 1, 2020.

If you’d like to make a deeper personal commitment to NBCC through a tax-deductible donation, please call our Development Office at 202.973.0569 or visit BreastCancerDeadline2020.org/Give.

Together, we can end breast cancer by 2020. Are you with us?

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**Here’s what a couple of our loyal supporters say about why they stand behind NBCC:**

“I lost both my breasts in 1992 and I’m still here. All these years I’ve been going around the country, talking to women, listening to women, talking to health care providers and listening to them, too. ‘We need a cure,’ everybody says. A cure? Sure. What we really need is a way to prevent breast cancer. It could happen. It’s got to. It’s time to do more. We need a deadline. Which is why I join my voice to the National Breast Cancer Coalition—to the voices of all the women saying, ’2020.’”

— Linda Ellerbee, Journalist

“We’ve spent billions of dollars on genomics, immunology and proteomics…it’s about time we started parlaying that toward real specific goals. The goal of eradicating breast cancer in 10 years.”

— Stephen Johnston, Director, Center for Innovations in Medicine at the Biodesign Institute, Arizona State University