

ANNUAL REPORT 2008



National Breast Cancer Coalition

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National Breast Cancer Coalition (NBCC) is a 501(c)(4) organization that lobbies through its grassroots network for increased funding for innovative research and a seat at the table to oversee how those funds are spent and for public policies to expand access to quality health care for all. NBCC designs and works to enact legislation, policy and regulation necessary to achieve our mission to end breast cancer.

NBCC Fund is a 501(c)(3) entity that designs and runs programs to educate, train and inform advocates, policy makers, scientists, providers and the public in science, health care and advocacy; collaborates with the research community on innovative research; effects change in the health care system to advance access to quality health care for all and gives a powerful, effective voice to breast cancer advocates everywhere.

NBCC's mission is to end breast cancer through action and advocacy.



## FROM THE PRESIDENT



Dear Friend of NBCC,

We are impatient. Impatient with those in power who tell us that breast cancer has enough funding, that existing treatments are adequate and that real health care reform will take time. We are impatient with those who are comfortable with the status quo, content with incremental progress and intimidated by politics.

That has never been NBCC's style or approach to our mission. We care less about how much funding exists than how those funds are spent. We want real progress toward life-saving treatments, not a trade-off between long-term toxicity and short-term improvement. And time is not the catalyst for real reform, *we are*, as one of the groups capable of mobilizing the political will to finally achieve access to quality care for everyone in this country.

This past year was a roller coaster: we held another successful Advocacy Training Conference and Lobby Day, bringing new and seasoned breast cancer advocates, public policy and science experts together for four days of learning, debating and advocacy. We convened our second International Project LEAD® in Paris, France and enjoyed the DC premiere of the Lifetime original movie *Living Proof*, which highlighted our research advocacy.

We finally saw the Breast Cancer Environmental Research Act—a piece of legislation we had worked on for close to a decade—come to a vote, only to have it dramatically altered and significantly weakened before passage. We were privileged to welcome former President Bill Clinton to our annual New York Gala and were humbled by his praise of our work and tenacity.

These highs and lows drive us to be impatient: how many more false starts like BCERA will there be? Why must we push for adequate research funding each year to ensure that the Department of Defense peer-reviewed Breast Cancer Research Program will continue?

Though we're impatient, we are not bowed. We will continue to demand innovative research models and adequate funding to properly deploy those models. We will continue to demand advocate participation throughout breast cancer decision-making processes and we will insist on access to quality health care for all.

Thank you for your support this past year. As part of the National Breast Cancer Coalition, you play an important role in all that we do. Through your support you enable us to speak for tens of thousands of individuals and hundreds of organizations that, as single voices, would go unheard. The Coalition will continue to amplify those voices and will challenge those who embrace the status quo.

Sincerely,

A handwritten signature in black ink that reads "Fran Visco". The signature is written in a cursive, flowing style.

Fran Visco

*In Memoriam*

M. Carolina Hinestroza

March 7, 1959–June 21, 2009



*With deep sadness, the National Breast Cancer Coalition  
mourns the passing of M. Carolina Hinestroza,  
Executive Vice President for Programs and Planning*

## A Note from Fran Visco

Carolina's passing leaves an unfathomable void for all of us, as a friend, a colleague, and a leader.

I had the gift of working with her for many years. Just a few days before she died, she told me how grateful she was for the incredible opportunities and experiences she had working with NBCC and felt blessed that she had the extraordinary opportunity to help change the world. We are grateful for the opportunity to have worked with her.

Her ongoing presence in our lives and mission will spur us forward, demanding we not let up, not give in and not rest until we have ended this disease.

## More About Carolina

As Executive Vice President of the National Breast Cancer Coalition, Carolina brought her extraordinary analytic skills and passion to bear on all of our work. She led Research and Quality Care Initiatives, spearheaded our health care reform efforts, and was a spokesperson on our behalf in many settings. She chaired the Integration Panel of the Department of Defense Breast Cancer Research Program, sat on several Institute of Medicine and Agency for Healthcare Research and Quality committees, including the National Advisory Board and the Effective Health Care Program Stakeholder Group, always speaking on behalf of patients and women at risk.

Carolina was a driving force behind the convening of a 2005 focused workshop on biomarker research, which resulted in the first, and to date only, advocate-authored article published in the journal, *Cancer*.

Born in Bogotá, Colombia, Carolina came to the United States in 1985 as a Fulbright Scholar to pursue a master's degree in economics at Western Illinois University. She worked as a business economist in Colombia and New Zealand before moving to the Washington area in 1993.

Following a breast cancer diagnosis in 1994, Carolina and a group of survivors and health care professionals formed *Nueva Vida*, the only comprehensive support network for Latinas with breast and cervical cancer

in the Washington metropolitan area. *Nueva Vida* continues to offer culturally relevant survivorship and access support to a largely immigrant community for whom the challenges of living in a foreign environment add to the burdens of a cancer diagnosis.

While Executive Director of *Nueva Vida*, Carolina brought the voice of Latinas with breast cancer to the national stage, representing her organization on the Board of Directors of the National Breast Cancer Coalition, the Integration Panel of the Department of Defense Breast Cancer Research Program and the National Cancer Institute's Central Institutional Review Board.

Additionally, she served on many national committees, including the Institute of Medicine's Committee on Technologies for the Early Detection of Breast Cancer, the Agency for Health Care Research and Quality, the National Quality Forum, the Ethical Force of the American Medical Association and the National Action Plan on Breast Cancer Consumer Involvement Working Group. Carolina also served as Chair of the Integration Panel of the Department of Defense Breast Cancer Research Program, the second consumer advocate to chair that panel since its founding. She also played a leading role in the development of the International Latina Breast Cancer Advocacy Network.

Carolina completed a Masters of Public Health, concentrating on health policy, at the George Washington University in Washington, D.C., in the spring of 2001.

She is survived by her husband, Michael Moses, and daughter, Isabel Hinestrosa of Bethesda, MD; parents Fabio and Marina Hinestrosa of Ibague, Colombia; siblings Martha and Marina of San Francisco, CA; Angela, of Ibague, Colombia; and Guillermo and Maria Cecilia of Bogotá, Colombia, and many family and friends around the world.

At the family's request, the National Breast Cancer Coalition has established a tribute fund to honor Carolina's memory. Those wishing to contribute can visit <http://www.StopBreastCancer.org/carolina> or can send contributions to NBCC, 1101 17th Street, NW, Suite 1300, Washington, DC 20036, Attention: M. Carolina Hinestrosa Memorial Fund.



New York advocates Joan Elmer and Marian Feinberg are enthusiastic about their Lobby Day 2008 Meetings

# ABOUT US



**LEFT:** Annual Advocacy Training Conference opening and dedication, April 2008

**MIDDLE:** Advocates raise important questions at workshop sessions at the 2008 Conference

**RIGHT:** NBCC Advocate Samantha Reed participates in the Quality Care Project LEAD program in Northern Virginia, February 2008

The National Breast Cancer Coalition has put breast cancer at the forefront of the nation's agenda by bringing over \$2 billion in new funding to innovative research and overseeing how that money is spent, collaborating with scientists to design research and set priorities, training thousands of advocates to proactively influence the decision-making processes in breast cancer, leading efforts to define quality breast cancer care and pushing for access to quality health care for all.

We bring hundreds of breast cancer organizations and thousands of advocates together under our umbrella to push for change on the national and community level. Our advocates are change agents, committed to ending breast cancer. We were the first breast cancer organization to publicly articulate that goal and have never wavered from it. We provide science and advocacy training to prepare women and men to assume a powerful role before legislative, scientific and clinical decision-makers, and increase the influence of breast cancer advocates in all aspects of the breast cancer decision-making process. We set an agenda for public policy, research and health care, then work to make it reality.

We act as the conscience in breast cancer and as a catalyst for the changes necessary to finally end breast cancer. We challenge accepted thinking and drive informed, evidence based assessments of scientific discovery, best practices and health care delivery models.

Our advocates collaborate with the scientific community on implementation of new research models as well as partner in the planning and execution of clinical trials, to expedite accessing care, finding the causes of and cures for breast cancer. Through our grassroots network, the Coalition has brought about fundamental change. These are just some of our accomplishments:

- Our activism has led to an increase in Federal appropriations for breast cancer of 600%;

- Our demand for innovative models of scientific research helped create an unprecedented breast cancer research program administered by the U.S. Department of Defense—the peer-reviewed Breast Cancer Research Program (DOD BRCP) that continues today;
- Our advocacy and collaborations with scientists 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 determination that knowledgeable advocates take their rightful place as decision-makers led us to create unprecedented programs to educate the public and to train more than 11,000 advocates who challenge the status quo and demand more from hospital boardrooms to Capitol Hill;
- 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, the Breast and Cervical Treatment Act.

Since our inception, NBCC has been a powerful voice for women and men across the country. As we advance our mission of eradicating breast cancer, three primary goals guide our work:

**RESEARCH:** to promote research into the cause of and optimal treatments and cure for breast cancer, through increased federal funding for meaningful research and innovative collaborations among scientists and advocates.

**ACCESS:** to improve access to high-quality breast cancer information, treatment and care for all women, particularly the underserved and uninsured. Legislation and changes in the regulation and delivery of health care are all critical in meeting this goal.

**INFLUENCE:** to increase the involvement and influence of those living with breast cancer and other breast cancer activists across all decision-making linked to breast cancer.

## 2008 HIGHLIGHTS



International Clinical Trials Project LEAD attendees: (left to right, bottom row) Sara McKenna (UK), Adrianna Kaufman (Argentina), Karima Elshamy (Egypt), Christine Brunswick (US); (top row) Bolivia Bocaranda (Venezuela), Michelle Marven (Australia), Diane Moore (Canada), Colleen Marco (South Africa)

### INTERNATIONAL CLINICAL TRIALS PROJECT LEAD®

Twenty-six students from 13 countries graduated from NBCC Fund's first International Clinical Trials Project LEAD, held in Paris, in December. Translational Research in Oncology (TRIO), a renowned international research organization, partnered with NBCC to bring this course to fruition.

Several core Project LEAD® faculty members were joined by prominent researchers from Belgium, France, and the United Kingdom to provide an international perspective. Faculty included Kay Dickersin, Ph.D., of Johns Hopkins University; Dennis Slamon, M.D., Ph.D., of UCLA; Ezekiel Emanuel, M.D., Ph.D., of NIH; Marc Buyse, Sc.D., of the International Drug Development Institute (IDDI); and Alan Morrison, MD of Amgen.

The week-long course was an exciting and remarkable training of breast cancer advocates aimed at encouraging advocate involvement in research and clinical trials work around the world.

### NATIONAL PHILANTHROPIC TRUST (NPT) AWARDS NBCC A MULTI-MILLION DOLLAR GRANT



In May, the National Breast Cancer Coalition was awarded a three-year, multi-million dollar transformational grant from the Breast Cancer Fund of National Philanthropic Trust (NPT). The grant will underwrite programmatic expansion and enable the Coalition to enhance its capacity in other areas.

Additions to NBCC's training platform will build on the highly respected Project LEAD model and expand into a regional delivery model. Other advocacy programs will be developed, including an introductory Project LEAD and a half-day introduction to NBCC workshop for those new to breast cancer advocacy, as well as Emerging Leaders, a dynamic program to engage young professionals and recent graduates.

### FRAMEWORK FOR A HEALTH CARE SYSTEM GUARANTEEING ACCESS TO QUALITY HEALTH CARE FOR ALL RELEASED

For several years NBCC, recognizing the complexities of reforming the U.S. health care system, has studied the many policy issues involved in such a change. After careful analysis of the issues, we recognize that what is needed to end breast cancer is comprehensive reform that provides access to evidence-based care for everyone, not just for one disease. Our grassroots activists are prepared to aggressively push for this vision to become a reality. NBCC's *Framework* envisions a health care system that covers everyone and pays for all the care an individual **needs**, not necessarily all the care they **want**. We envision a system that will pay for care that is effective, both in terms of efficacy and cost, and care that is based on quality evidence, with a non-political federal-level board authorized to make many of these decisions.



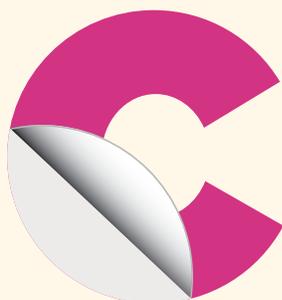
### PRESIDENTIAL CAMPAIGN

NBCC knows that breast cancer is a political issue, and we are proud to have pushed it to the forefront of the national political agenda. Two months prior to the first presidential contests in Iowa and New Hampshire, the NBCC launched the Breast

Cancer Caucus ([www.BreastCancerCaucus.org](http://www.BreastCancerCaucus.org)). This online resource is a unique source for voters that contains videos and written statements from Presidential candidates of both parties, detailing their specific approaches to breast cancer research, prevention and care as well as their plans for health care reform.

The Breast Cancer Caucus featured videos and written statements of participating candidates describing their support for NBCC's agenda and what they would do to end breast cancer if elected.

## INTRODUCTION OF A NEW BRAND IDENTITY



After a thoughtful process of gathering member and public input, NBCC developed a new brand identity to be launched in 2009.

The NBCC brand is so much more than a logo—it is a mission, a culture and a set of values that embody how we approach this vital work.

The curling C symbolizes that NBCC Advocates are the change agents who are first and foremost committed to “ripping” breast cancer away for good.

It also shows our willingness to look beyond and below the pink of awareness to see what's really happening in breast cancer—where we've come and where we've yet to go.

Finally, the logo demonstrates our commitment to “looking beneath the surface” to examine the science, public policy and health care delivery systems and acting as the conscience and catalyst for the changes necessary to end breast cancer.

## THE ENVIRONMENT AND BREAST CANCER

In 2008, both the House and the Senate approved the Breast Cancer Environmental Research Act (BCERA), but passed a version of the bill that was not the same that had the support of NBCC, or of 287 Members of Congress and 70 Senators. The bill that ultimately was enacted into law did not accomplish the goals set out by the NBCC-supported legislation, nor did it create a grant program or structure that would produce a coherent, national strategy to address the possible links between breast cancer and the environment. Read more about BCERA and other legislative news on page 19.

## FORMER PRESIDENT BILL CLINTON SPEAKS AT NEW YORK GALA

NBCC was honored to welcome former President Bill Clinton to our 13th Annual New York Gala held November 10, 2008 at Cipriani 42nd Street. See more photos from the event on page 23.

*“We need the National Breast Cancer Coalition. And we need Americans who can maintain their commitment to help to empower private citizens to do public good. Nobody does it better than Fran Visco and her allies.”*



## LIVING PROOF SCREENING

On September 25, 2008 at the Historical Society of Washington, D.C., NBCC welcomed friends and supporters to a star-studded screening and reception of Lifetime's original movie, *Living Proof*. Based on Robert Bazell's 1998 book, *Her2*, about the development of the breast cancer drug, Herceptin, the film highlighted the National Breast Cancer Coalition's important role in Herceptin's clinical trials. The role of Fran Visco was played by Amy Madigan (*pictured together below*), and Harry Connick, Jr. played long-time NBCC partner and breast cancer innovator, Dr. Dennis Slamon.



## AN UNYIELDING FOCUS ON RESEARCH



Project LEAD participants, February 2008

From its earliest days, NBCC has known that focusing on leading-edge research—the kind that takes bold risks in hopes of significant progress, that dares ask the novel questions to achieve the greatest good—has the most potential for producing a notable and overarching impact on breast cancer.

The Department of Defense peer-reviewed Breast Cancer Research Program, NBCC's initial effort to dramatically increase federal funding for innovative, multi-disciplinary, high-impact breast cancer research, has invested over \$2 billion in new research funding, proven the value of trained advocate engagement in research processes and introduced new research models now adopted throughout the scientific community.

### DEPARTMENT OF DEFENSE BREAST CANCER RESEARCH PROGRAM

NBCC's advocacy led to the creation the Department of Defense Breast Cancer Research Program (DOD BCRP). As a direct result of NBCC grassroots efforts, more than \$2 billion

has been allocated to peer-reviewed breast cancer research through this program since 1992. In 2008, the program was funded at \$160 million and NBCC Executive Vice President of Programs and Planning, Carolina Hinestrosa, chaired the Integration Panel that sets the vision for the Program. At NBCC's demand, advocates continue to be involved at all levels of the program, with many trained by NBCC through Project LEAD.

### ERA OF HOPE

The 2008 Era of Hope meeting, part of the Department of Defense Breast Cancer Research Program, took place in June in Baltimore, Maryland. This remarkable gathering brought together over 1550 scientists, clinicians, breast cancer advocates and policy makers from over 530 organizations.

This year's theme was *Time for Action* and focused on three topics: *Risk and Prevention Across the Spectrum of Breast Cancer*, *Breast Cancer Diagnosis—What's on the Horizon* and *Managing Breast Cancer Across the Spectrum of the Disease*. NBCC president Fran Visco moderated the opening

*"It is an incredible experience to interact with scientists as peers and to realize the extent to which advocate thinking and observations can help influence and improve the direction of research. This made the conference and the process so powerful," commented Amy Bonoff, NY advocate, first-time attendee and presenter at the Era of Hope meeting.*

Era of Hope Blog ■ 1600 Advocates & Researchers Attend 2008 Era of Hope Meeting ■ Posted: July 10, 2008

session with Bob Bazell, NBC News' Chief Science and Health Correspondent. She challenged the scientists from her opening remark: "What have you been doing for the past 10 years?" as to why we are not further along in finding a cure for breast cancer.

Over 1200 BCRP-funded research projects were displayed in poster sessions. Unlike many other programs, researchers receiving funding from the DOD BCRP are required to report their results, whether they are positive or negative. This level of transparency and candor is a hallmark of the DOD BCRP and, for the rest of the research world, a lesson.

Another key strength of the Era of Hope, and by extension the DOD BCRP, is its unprecedented level of advocate involvement. True to the spirit of the DOD BCRP, the Era of Hope includes consumer advocates at all levels, standing shoulder to shoulder with scientists and researchers. In 2008, 72 survivors were speakers, co-chairs or moderators of sessions, and 15 survivors presented abstracts.

## TRIBUTE TO COLONEL HARRIS



Colonel Janet R. Harris, MSN, Ph.D., left her post as Director of Congressionally Directed Medical Research Programs—the military department that oversees the DOD BCRP—in 2008. NBCC thanks Col. Harris for her support of the DOD Breast Cancer Research Program over the past three years. She

directed breast, prostate and ovarian cancer programs as well as other peer-reviewed medical programs for the US Army Medical Research and Material Command. Col. Harris' strong leadership helped the DOD Breast Cancer Research Program reach many successes.

## DEPARTMENT OF DEFENSE BREAST CANCER RESEARCH PROGRAM CONGRESSIONAL FORUM

Capitol Hill Briefing ■ February 11, 2008

NBCC hosted a standing-room-only crowd of staff from both the House and the Senate who came to learn more about the Department of Defense peer-reviewed Breast Cancer Research Program (DOD BCRP). The Forum's Honorary Host Committee included Senators Harkin (D-IA), Snowe (R-ME), Leahy (D-VT), Specter (R-PA) and Collins (R-ME) and Representatives Nita Lowey (D-NY), Judy Biggert (R-IL), Jim McGovern (D-MA), and Tom Davis (R-VA).

M. Carolina Hineostroza, NBCC's Executive Vice President of Programs and Planning, opened the Forum with an overview of the history of NBCC, focusing on its involvement with the DOD BCRP. She discussed how this Program works to fill the need for more innovative research. Finally, she asked Members of Congress to sign the letter to Appropriators asking for funding of \$150 million for the Program.

Col. Janet Harris, Director of the Congressionally Directed Medical Research Programs, Department of the Army gave a presentation on the structure of this peer-reviewed research Program, including a detailed review of the model grant mechanisms it has developed since it began in 1992. Col. Harris described the Program's groundbreaking successes and the promising emerging research. She also spoke about the importance of consumer reviewers on the decision-making process at the Program.

Rosemary Rosso, NBCC Board Member and DOD BCRP Peer Reviewer explained in lay terms the peer review process and how important it is to have consumers at the table in order to find not only the most scientifically meritorious proposals, but also those that are the most innovative and will have the most impact on breast cancer. She described how NBCC Fund's Project LEAD teaches breast cancer survivors the science of the disease and prepares them to participate on peer review boards.

Through NBCC advocacy, DOD BCRP was funded at \$138 million in fiscal 2008. Our tenacious grassroots advocacy resulted in a \$12 million dollar funding increase for the fiscal 2009 budget for a total of \$150 million.



Carolina Hineostroza presents at the Capitol Hill Briefing

## Newsweek

*"We ask the scientists all the time, 'why aren't we further along?'" says Visco.*

*"Part of the answer is that the infrastructure of cancer is to keep things moving along as they have been and to reward people for doing safe research. Exciting new ideas haven't fared well."*

Fran Visco ■ Newsweek, *We Fought Cancer...And Cancer Won.* ■ September 15, 2008

### CLINICAL TRIALS INITIATIVE

NBCC continues to work with research organizations to improve trial design, increase access and accrual, and educate the medical community and consumers about the importance of high quality breast cancer trials. Activists trained through Project LEAD work with investigators, the National Cancer Institute (NCI) and other research institutions to move important trials forward, create accountability and spur innovation.

### INTERNATIONAL CLINICAL TRIALS

The International Clinical Trials Network focuses on the goal of bringing NBCC's unique and well-respected science-based advocacy to the global arena to ensure that breast cancer research everywhere is informed by educated, trained advocates who are able to participate in scientific collaborations.

In December 2008, NBCC partnered with the Translational Research in Oncology (TRIO), a global network of oncology researchers, to host the first International Clinical Trials LEAD course in Paris, France. NBCC's President Fran Visco currently serves on the TRIO Board. Read more about the Clinical Trials Project LEAD on page 15.

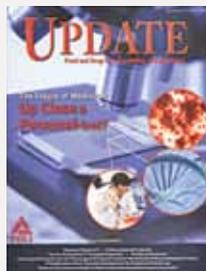
*"The challenge is how to translate promising data into evidence-based clinical interventions and how to assure that biomarker research includes the development of the necessary assays and targeted therapies in tandem."*

Excerpt from *Personalized Medicine: A Patient Centered Perspective*

By M. Carolina Hinestrosa

Food & Drug Law Institute Update Magazine

September/October 2008



### NETWORK OF INTERNATIONAL ADVOCATES

Breast cancer research is global and collaborations among trained advocates and investigators are necessary everywhere. Clinical trial design, safety and ethics, standardization and reporting are not unique to the United States; they are global challenges that need worldwide attention. NBCC has launched a network of international advocates to provide the global mentorship, networking and partnerships needed to make significant progress toward the mission to end breast cancer.

### AN EXAMPLE OF ONE CLINICAL TRIAL

NBCC continues to partner with the Eastern Cooperative Oncology Group (ECOG) and the National Cancer Institute (NCI) on TAILORx, a clinical trial that seeks to determine whether certain women with early stage breast cancer can forego chemotherapy. NBCC advocates are serving with investigators on the Steering Committee and Data Monitoring Board as well as conducting educational outreach for trial participation.

### BEYOND THE HEADLINES

NBCC's Beyond the Headlines is the go-to source for thoughtful, timely, patient- and evidence-centered responses to new breast cancer research and controversies. One key topic this year was Avastin, a targeted anti-angiogenic therapy that blocks the formation of blood vessels. The FDA approved this drug despite their advisory committee's recommendation against it. NBCC provided a detailed analysis of the relevant data, and advocated for a more cautious approach, given the seriousness of side effects. NBCC also testified to Oncology Drugs Advisory Committee (ODAC) about Erythropoiesis-stimulating agents (ESAs), a supportive therapy used to address the anemia associated with chemotherapy. NBCC fought to ensure that the public was aware of the risks this therapy poses to breast cancer patients. NBCC continues to monitor ongoing research on the use of Magnetic Resonance Imaging (MRIs) for breast cancer screening and diagnosis, as well as on the safety of chemicals in consumer plastics. We attend and report back on presentations and discussions at major scientific meetings and offer continuing education opportunities at these events and our own, for example, the San Antonio Breast Cancer Symposium, and our Annual Advocacy Training Conference.

## CONSUMER SURVEY

In October, NBCC published the results of our annual consumer survey and findings were published in *Prevention* Magazine (March 2008). The survey measures the general knowledge of breast cancer among American women. This year, as in last year, the results indicate a consistent misunderstanding of key facts about breast cancer, underlining NBCC's push to move beyond awareness into more rigorous public education.



### WHAT RESPONDENTS DID KNOW:

- ▶ Three out of four women correctly stated that the majority of breast lumps that are biopsied are found to **not** be malignant (cancerous). (76 percent, down from 85 percent in 2007)

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- ▶ The majority of women correctly believe that the lifetime risk of dying from breast cancer is less than it was 15 years ago. (62 percent, up from 60 percent in 2007)

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- ▶ More than two out of three women agree that the lack of evidence-based and easy to understand information for patients is hurting the fight to eliminate breast cancer.

### WHAT RESPONDENTS DID NOT KNOW:

- ▶ Women continue to mistakenly believe that one in eight women will be diagnosed with breast cancer each year. (86 percent, up from 83 percent in 2007)
  - In fact, the actual statistic is based on lifetime risk and is correctly stated as “1 in 8 women will be diagnosed with breast cancer *during their lifetime*.”

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- ▶ Women continue to mistakenly believe the most common predictors of breast cancer are a genetic pre-disposition and family history (75 percent, up from 63 percent in 2007) with nearly 2 in 3 incorrectly believing the myth that 75% of those diagnosed with breast cancer have a family history of the disease.
  - In fact, over two-thirds of women diagnosed have no known risk factor. Even though having an inherited mutation in certain genes is the most potent risk factor, the National Cancer Institute states: “these genes are rare in the general population and are estimated to account for no more than 5% to 10% of breast and ovarian cancer cases overall.”

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- ▶ Most women believe that having a healthy diet rich in fruits and vegetables is an effective way to reduce breast cancer risk. (74 percent, up from 70 percent in 2007)
  - Recent studies have not been able to consistently identify a significant link between increased vegetable and fruit consumption with a decrease in breast cancer incidence. However, there obviously are many other health benefits to having a diet rich in fruits and vegetables.

## A COMMITMENT TO ACCESS AND QUALITY



Fran Visco introduces NBCC's *Framework for a Health Care System Guaranteeing Access to Quality Health Care for All*

**N**BCC has long believed that a key component necessary to end breast cancer is consistent access to the highest-quality health care and the information necessary to make informed choices about health and treatment. With the change of the country's leadership in 2008, NBCC will once again advocate for this coverage, consistent with our principles of health care reform adopted in 2003: access, choice, respect, information, accountability and improvement.

NBCC's *Framework for a Health Care System Guaranteeing Access to Quality Health Care for All* serves as an important roadmap, and NBCC continues to promote the adoption of our core values.

### **FRAMEWORK RELEASED AT 2008 CONFERENCE**

Access to quality care for all is critical to ending breast cancer. Through a thoughtful and dynamic process that spanned several years, the Coalition developed a *Framework for a Health Care System Guaranteeing Access to Quality Health Care for All* to guide a legislative approach to coverage issues. The *Framework* was unveiled at the 2008 Advocacy Training Conference held April 26–29th in Washington, D.C.

“Recognizing the complexities of reforming the U.S. health care system, our organization has spent several years studying the many policy issues involved. We have carefully analyzed the

issues and we recognize that what is needed to end breast cancer is comprehensive reform that provides access to evidence-based care for everyone, not just for one disease. Our grassroots activists are prepared to aggressively push for this vision to become a reality,” said Fran Visco.

A health care system that is built on this *Framework* will:

- provide a basic benefits package that is comprehensive and based on sound scientific evidence;
- maintain continuity of coverage;
- be efficient and cost-effective;
- be fully-funded through shared financial responsibility;
- be sustainable and affordable.

The health care system must be accountable to the users and the public. A system must be established to:

- evaluate and support development of medical evidence for health interventions upon which coverage will be based;
- support ongoing and continuous comparison of interventions to ensure access to appropriate and cost-effective healthcare;
- modify and expand current benefits as appropriate based on evidence.

The *Framework* was used as a central discussion topic at over 400 Lobby Day appointments held by NBCC’s advocates. As health care reform is taken up by Congress and the White House, NBCC expects to play a central role in the process by bringing an informed patient perspective and aggressively pushing for NBCC-endorsed aspects of quality care. For more information about our work on health care reform and our view of quality care, visit <http://www.StopBreastCancer.org>.

## STAKEHOLDER MEETING

In early 2008, NBCC convened a meeting of key stakeholders in health care reform. At NBCC’s invitation, policymakers, consumer groups, insurance organizations, provider associations and unions gathered to hear a presentation about our *Framework for a Health Care System Guaranteeing Access to Quality Health Care for All*. Attendees offered feedback on the *Framework* health care before breaking out into small groups to analyzing the document section-by-section.

## MEASURING WHAT MATTERS and NBCC’S QUALITY CARE INITIATIVE

The goal of NBCC’s Quality Care Initiative is to increase access to and improve the quality of breast cancer care for everyone. The Initiative is guided by NBCC’s patient-centered, evidence-based vision of quality care and espouses six overlapping core values:

- Access to all the care you need when you need it
- Information that is complete and correct
- Choice about your doctors and your treatment
- Respect from everyone in the health care system
- Accountability so there is a way to fix problems
- Improvement in the system so breast cancer care continues to get better

To achieve the goal of quality care for all, we focus educating breast cancer patients, advocates and the public at large about what quality breast cancer care is, how best to get it right now, and how to effectively advocate for quality care. An outgrowth of this work is the *Measuring What Matters*® program.

NBCC believes that publicly reported measures of care could dramatically improve the quality of breast cancer care—and health care in general—in the United States.

NBCC has continued its work on the *Measuring What Matters* project to identify what should be measured in breast cancer care, what is currently measured, and how to address the gaps.



Through a collaborative process led by patient advocates and involving a wide range of other stakeholders, the Coalition developed a core set of measurement indicators that address the key components of breast cancer quality care. Some of these measures currently exist, while others will need to be developed.

The Coalition’s ultimate goal is the creation of a small, balanced set of measures that reflect the NBCC core values of quality health care and can be used throughout the country in most health care settings.

# PROGRESS THROUGH INFLUENTIAL LEADERSHIP



Emerging Leaders meet at the Annual Advocacy Training Conference, April 2008

**The New York Times** *“We believe that they [FDA] have lowered the bar,” said Fran Visco, president of the National Breast Cancer Coalition Fund, a patient advocacy group, which had opposed approval [of Avastin]. “Our goal is to get the best treatments out to patients that really will be effective and safe. This particular circumstance will not advance that goal.”*

Fran Visco ■ New York Times, *Wider Use of Avastin is Approved* ■ February 23, 2008

**B**efore the Coalition, organized, informed patient advocacy was lacking in the cancer community. Today, more and more scientists and decision-makers have come to value the perspective of well-trained, thoughtful and engaged breast cancer advocates. The National Breast Cancer Coalition is respected for the extensive, thorough and rigorous training we provide. Through an array of programs—Project LEAD, the Advocacy Training Conference, Team Leader Training and Emerging Leaders initiatives—our advocates receive sound education in science, public policy, research practices and modalities and the political process needed to give them a meaningful role in the research and health care decision-making processes. NBCC is represented on a broad array of national committees and mentors other organizations so they too can develop committed advocacy leaders, increasing the reach and diversity of trained breast cancer advocates able to lend their voices and energies to eradicate breast cancer.

## NBCC ADVOCATES: EVERYWHERE BREAST CANCER DECISIONS ARE BEING MADE

NBCC trains its advocates to be leaders whenever and wherever breast cancer decisions are being made, whether in local research facilities or the corridors of power in Washington. Here are some of the decision-making consortia, committees and coalitions where you'll find our advocates:

- ▶ Agency for Health Care Research and Quality (AHRQ), National Advisory Board, Effective Health Care Program Stakeholder Group (Chair, Regulations)
- ▶ American Medical Association Ethical Task Force
- ▶ Breast Cancer International Research Group (BCIRG) Scientific Advisory Board, Member of Independent Data Monitoring Board for trials 005 and 006
- ▶ Cochrane Collaboration Consumer Coalition
- ▶ Department of Defense Breast Cancer Research Program (DOD BRCP) Integration Panel (including 2009 Chair)

- ▶ Institute of Medicine (IOM) Committee on Comparative Effectiveness Research Priorities
- ▶ Institute of Medicine Roundtable on Evidence-Based Medicine
- ▶ Love/Avon Army of Women Steering Committee
- ▶ Markle Foundation, Connecting For Health
- ▶ National Accreditation Program for Breast Centers, American College of Surgeons Access and Utilization Strategic Planning Committee
- ▶ National Quality Forum, Breast Cancer Technical Panel
- ▶ NQF Clinician Level Cancer Care Steering Committee
- ▶ TAILORx Clinical Trial Steering Committee and Data Safety Monitoring Board
- ▶ Breast Cancer and Environment Research Centers Working Group Members

## OUR PROGRAMS

NBCC's rigorous and unique education and training programs continued to evolve and expand in 2008. A new international program was initiated and the creation of a new umbrella structure to house the family of Project LEAD courses along with a whole set of new programs that will take shape in 2009. The following programs occurred in 2008:

The third **Quality Care Project LEAD®** took place in February in Northern Virginia with 26 students. This course is aimed at advocates interested in changing health care systems and understanding the tools used in health services research to measure and improve quality of care. Students studied and analyzed concepts crucial to healthcare reform such as organizational change theory, health information technology, quality care measures and comparative effectiveness.

The 16<sup>th</sup> **Advocacy Training Conference** took place April 26 – April 29, 2008 at the Renaissance Hotel in Washington, D.C. with 614 attendees. Participants came from around the country and from 9 countries. Plenaries focused on research health care reform and the politics of breast cancer and a new interactive café introduced blogging, surveys and video diaries as a way to communicate to the broader breast cancer community.

The **Project LEAD® Institute** was held in July in Colorado and graduated 48 students. The Institute teaches the concepts and language of science including sessions on molecular biology, genomics and proteomics, genetics, epidemiology, research design and biostatistics. Students emerge from the course with an Action Plan and a mentor to help guide them to become active research advocates. This course also featured a hands-on laboratory experience at the University of Colorado Comprehensive Cancer Center.

An advanced course open to Project LEAD graduates, **Clinical Trials Project LEAD®** is focused on teaching students the

Fran Visco ranks 20th in the top 40 most influential people in the global pharmaceutical industry.

**PHARMA 40 2008**

**THE FINAL LIST**

1 <b>Mario R Capucci, Sr</b> , chairman and CEO, Genentech, Nobel Prize winners	21 <b>Mahinder Mohan Singh</b> , CEO and managing director, Ranbaxy
2 <b>Arthur Levinson</b> , chairman and CEO, Genentech	22 <b>Jean-Pierre Garrier</b> , outgoing CEO, CSE (retires May 2008)
3 <b>Bill and Melinda Gates</b> , co-founders, Bill and Melinda Gates Foundation	23 <b>Professor Rolf Knebel</b> , scientist and author
4 <b>Dr Margaret Chan</b> , director general, World Health Organization	24 <b>Ranjit Shahani</b> , president, Organisation of Pharmaceutical Producers of India
5 <b>Sir Michael Rawlins</b> , chairman, NICE	25 <b>Warner Buffett</b> , philanthropist
6 <b>Andrew Witty</b> , incoming CEO, GlaxoSmithKline	26 <b>Carl Icahn</b> , investor
7 <b>Senator Charles E Grassley</b> , chairman, Senate Finance Committee	27 <b>Craig Venter</b> , president, J Craig Venter Institute
8 <b>Thomas Lengua</b> , executive director, EMEA	28 <b>Jean-François Dubouché</b> , chairman and CEO, sanofi aventis
9 <b>Bill Clinton</b> , founder, Clinton Foundation	29 <b>Elmer E Huerta</b> , president, American Cancer Society
10 <b>Shiloma Yanai</b> , president and CEO, Teva Pharmaceuticals	30 <b>Mark Walport</b> , director, Wellcome Trust
11 <b>Jeffrey Kiedler</b> , CEO, Pfizer	31 <b>Gregory J Hanson</b> , scientist and researcher
12 <b>Dietmar Hopp</b> , entrepreneur and philanthropist, SAP	32 <b>Fred Rissan</b> , chairman and CEO, Schering-Plough Corporation
13 <b>Dr Christopher Liggett</b> , executive research fellow, Pfizer	33 <b>Harvey Rabe</b> , director general, IFMA
14 <b>Richard Reichman, William Bonnez and Robert Rose</b> , University of Rochester	34 <b>Marvin Carsthus</b> , professor, University of Colorado
15 <b>Nancy Pelosi</b> , speaker, US House of Representatives	35 <b>Ramesh Reddy</b> , chairman, Aurobindo Pharma
16 <b>Dr M Venkateswara</b> , drugs controller general of India	36 <b>M Cass Wheeler</b> , CEO, American Heart Association
17 <b>Shao Mingli</b> , commissioner of the State, FDA, China	37 <b>Ronald D Luff</b> , director anatomical clinical trials, Quest Diagnostics
18 <b>Dr Janet Woodcock</b> , director, FDA CDER	38 <b>Richard T Clark</b> , chairman, president and CEO, Merck & Co
19 <b>Billy Tauzin</b> , president and CEO, PHRMA	39 <b>Dr Roger L Williams</b> , executive vice president and CEO, US Pharmacopeia
20 <b>Frances M Visco</b> , president, National Breast Cancer Coalition	40 <b>Rajesh Jain</b> , joint MD, Pfizer, Biogen

**KEY**   
 Top Ten 2007   
 Newcomer 2007   
 New entrant

14 WorldPharmaceuticalFrontiers | www.worldpharmaceuticalfrontiers.net

**20** **Frances M Visco**, president, National Breast Cancer Coalition

intricacies of the clinical trials process, its phases and stages, the methodological and ethical issues involved and the role of advocates in the process.

December 3-6, 2008 in Paris, France, 26 students from 12 countries took part in **International Clinical Trials Project LEAD**. A program of NBCC's Clinical Trials Initiative, the goal is to train a cadre of advocates to work with breast cancer researchers in their respective countries, such as members of the Translational Research In Oncology (TRIO) group which helped sponsor the course.

NBCC's unique **Team Leader Training** program brings a select group of breast cancer advocates from around the country to Washington for intensive training and development. Training focuses on grassroots advocacy, the federal legislative process, NBCC legislative and public policy agenda, and lobbying techniques. The goal of Team Leader Training is to build a cadre of NBCC activists who are fluent in and committed to carrying forward the NBCC agenda for an entire Congress and in their state throughout the year.



## PROJECT LEAD INSTITUTE

In late summer, 53 advocates from 22 states attended the Project LEAD Institute— a more in-depth and challenging version of NBCC’s landmark science training program—at the Inverness Conference Center near Denver, Colorado. The intensive curriculum included lectures and study sessions on the molecular biology of cancer, genetics, epidemiology of cancer, research design, and critical appraisal of scientific literature. Project LEAD continues to be a groundbreaking program that provides advocates with the information they need to provide informed opinions about best methods in research and legislation.

### Gail Armanini attended and graduated from the Project LEAD Institute in 2008. These are her thoughts on that experience:

Knowledge is power, and nowhere is this more evident than in the world of breast cancer advocacy. Much of my advocacy work is in the area of breast cancer education, and it is imperative that the information I provide is accurate. Without a science or medical background, I often felt at a loss to convey the type of information I knew would serve my audience best.

NBCC’s Project LEAD Institute surpassed anything I could have imagined in terms of disseminating the information I need, and the tools to apply it, in my advocacy work. Starting with basic

science, and then moving on to genetics and epidemiology, we all came out of Project LEAD with a solid understanding of the biology of breast cancer, the genetic components of breast cancer, as well as the science of epidemiology and how it is used to study specific genetic or biologic theories in cancer research. For me, the highlight of Project LEAD was a field trip to the University of Colorado Cancer Center where we got to see, in action, all the principles of cancer biology and research we had been studying. That was my “aha” moment, when everything came together.

Another concept that I took away from Project LEAD is the importance of evidence-based health care and how quality research acts as the foundation in setting the standards. Learning about how research funding is acquired and the indispensable role consumer advocates play in the grant proposal review process has inspired me to pursue this area of advocacy as well. Another component of Project LEAD that I found invaluable was the preparation of our action plan. Working with my mentor to distill the hundreds of options available to LEAD grads into a manageable six-month plan has helped me immensely in focusing my energy towards my long term goals of patient education and the grant review process.

I will be forever grateful to have had the opportunity to learn from world-renowned researchers, whose passion about the eradication of breast cancer is palpable. Project LEAD challenged me to take on new roles in advocacy, and with the guidance of NBCC and the Project LEAD Director and mentors, I know I will succeed.

A one day program, **Speak Out to End Breast Cancer: A Breast Cancer Advocacy Workshop**, was piloted in 2008 in Philadelphia and Los Angeles to bring more people into the NBCC Advocacy training pipeline. The Speak Outs introduce new advocates to NBCC’s approach to research and public policy advocacy and include a session on a leading-edge breast cancer research topic. Speak Outs will take place in 4 cities in 2009.

## BEST PRACTICES AWARDS



If you’re medically underserved or uninsured in this country, finding health care services is a daunting, if not impossible, task. However, a Houston-based organization, The Rose’s Breast Health

Collaborative of Texas (BHCT), improved access to breast health services for this population, and serves as a model for other communities.

For this success and others, they received NBCC’s 2008 *Best Practices in Breast Cancer Advocacy Award*.® These awards

are given to a consumer-led grassroots advocacy organization whose strategic, high-impact programs address critical issues in the systems of research, access to quality care and public policy in breast cancer and should be replicated. The Collaborative received \$50,000 as the 2008 Best Practices winner, generously funded by the Breast Cancer Fund of National Philanthropic Trust.

The National Breast Cancer Coalition Fund launched the Best Practices Awards program in 2006. Past winners are: Alamo Breast Cancer Foundation, San Antonio, TX; Breast Cancer Alliance of Greater Cincinnati, Cincinnati, OH; Georgia Breast Cancer Coalition Fund, Atlanta, GA; Inflammatory Breast Cancer Research Foundation, Bainbridge Island, WA; Linda Creed Breast Cancer Foundation, Philadelphia, PA; New York State Breast Cancer Network, Spencer, NY; The Rhode Island Breast Cancer Coalition, Coventry, RI The Catherine Peachey Fund, Warsaw, IN; Nueva Vida, Washington, DC; SHARE, New York, NY; and Young Survival Coalition, New York, NY.

## NBCC AT THE SAN ANTONIO BREAST CANCER SYMPOSIUM

NBCC held its first Project LEAD Advanced Topics session prior to the opening of the San Antonio Breast Cancer Symposium in December 2008. Over 65 LEAD graduates attended a pair of

lectures given by LEAD faculty Paula Vertino and Diane Palmieri on signal transduction and epigenetics. The sessions were captured on a CD-ROM given to all attendees.

NBCC also held its second annual LEADers Dialogue at the end of the Symposium, with nearly 50 advocates in attendance. The session was moderated by Christine Brunswick and panelists included Musa Mayer, Maria Wetzel and Jane Perlmutter who presented a few of the advocate and scientific issues that emerged from conference presentations, including research on biomarkers, imaging, and metastatic disease. As is the hallmark of NBCC's Project LEAD training, lively audience discussion and a thought-provoking question and answer session concluded the discussion.



*“Advocates are very knowledgeable about where we’re at and where we’re going in research. They can discuss this on a personal level, on a policy level and on a scientific level, which is a direct result of the quality and strength of Project LEAD.”*

Dr. Dennis Slamon  
Department of Medicine, UCLA  
Discussing the value of the Project LEAD program

## ADVOCACY TRAINING CONFERENCE

*“When you invite people to think, you are inviting revolution.”*  
– Ivone Gebara

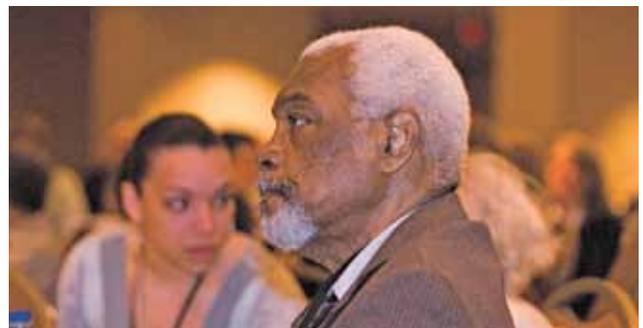
For 3 intense days, more than 600 advocates prepared themselves with the latest information on breast cancer research, quality care and access, and the politics of healthcare. The 2008 Conference featured 27 in-depth workshop sessions and excellent plenary speakers, including Dr. Susan Love, Dr. Otis Webb Brawley and keynote speaker, Eleanor Clift, of *Newsweek Magazine*.



At the Annual Membership Luncheon, The National Rural Letter Carriers' Association Auxiliary was honored with the Community Fundraising Award for its Program of Empowerment. Under the

guidance and enthusiasm of **Leanne Cook**, past president of the National Rural Letter Carriers' Association Auxiliary, its members and their families raised a total of \$83,000 for NBCC Fund.

NBCC also unveiled the newly developed *Framework for a Health Care System Guaranteeing Access to Quality Health Care for All*, important guidelines recommended to achieve effective health care reform.



**TOP:** Denise Smith Jones's father looks on during a moment of silence in her honor at the 2008 Advocacy Training Conference



**MIDDLE:** Chris Norton, NBCC Board Member opens the 2008 Conference

**BOTTOM:** Moderator, Abigail Trafford and panelists Dr. Susan Love, Pat Steeg, Don Berry and Carolina Hinestrosa take part in the “So What’s New in Breast Cancer?” Opening Plenary Session





Representative Ileana Ros-Lehtinen (R-FL) discusses NBCC priorities

*“The Breast Cancer and Environmental Research Act is vital to finding the cause of breast cancer so we can prevent it. Much of the research done in this country looks for new drugs to treat disease. That is needed. But we need to prevent breast cancer from starting and government funding is required to accomplish that goal. There is little financial incentive to fund this research elsewhere,”*

—Fran Visco

### A RIGOROUS AND THOUGHTFUL APPROACH TO SETTING PRIORITIES

The NBCC Board of Directors establishes our annual Legislative and Public Policy Priorities each year. The organization seeks input from all member organizations as to what priorities NBCC should advocate for in any given year.

NBCC chooses its priorities through a rigorous, thoughtful process. First, issues are brought to the attention of NBCC

leadership for consideration. All issues are brought to the attention of NBCC leadership for consideration and are researched by NBCC staff, who then prepare background information. The Board discusses all suggested priorities along with any others presented from the floor and votes on which NBCC will adopt. A final vote decides the rank order of the adopted priorities. The 2008 Legislative priorities are listed on the following page.



*"I want to know what causes this disease—for me, and for the 2.3 million others who share this diagnosis. We need more resources to figure out what the environment has to do with it."*

Sheryl Crow

Testifying before the Health Subcommittee of the House Energy and Commerce Committee on behalf of NBCC regarding BCERA

May 21, 2008

## 2008 LEGISLATIVE PRIORITIES

### Priority #1

#### **Guaranteed Access to Quality Health Care for All.**

We will not achieve our mission of eradicating breast cancer until everyone has guaranteed access to quality health care. NBCC's Board of Directors adopted a *Framework for a Health Care System Guaranteeing Access to Quality Health Care for All* in 2007, after extensive analysis and deliberation. This *Framework* builds on NBCC's longstanding principles and core values for quality health care. NBCC will use this *Framework* to educate and mobilize grassroots advocates to demand political leadership and action towards comprehensive health care reform.

### Priority #2

#### **\$150 million for FY09 for the Department of Defense Breast Cancer Research Program.**

As a result of NBCC's advocacy and strong bipartisan leadership on Capitol Hill, more than \$2 billion has been invested in this competitive peer-reviewed research Program. This innovative Program has changed the world of breast cancer research. The inclusion of consumers in every aspect of decision-making and the Program's unique grant opportunities have led to groundbreaking scientific advances.

### Priority #3

#### **Enactment of the Breast Cancer and Environmental Research Act (S.579/H.R.1157).**

It is generally believed that the environment plays a role in the development of breast cancer, but the extent of that role is not understood. The Breast Cancer and Environmental Research Act (BCERA) would establish a national strategy for investigating the impact of environmental factors on the development of breast cancer. BCERA would fund competitive, peer-reviewed, collaborative research through a process that includes consumer and community participation. This bipartisan bill has incredible political and grassroots momentum and is long overdue for passage.

### Priority #4

#### **Preservation of the Medicaid Breast and Cervical Cancer Treatment Program (BCCTP).**

While NBCC pursues its work on guaranteeing access to quality health care for all, we are committed to making sure women with breast cancer have access to the care they need. The BCCTP provides enhanced

matching funds to states to provide full Medicaid coverage to low-income, uninsured women screened and diagnosed with breast and/or cervical cancer through a federal program. All 50 states and the District of Columbia have opted into the program, but efforts to reduce funding for Medicaid or dramatically alter the program threaten the future of the BCCTP. NBCC will work to protect and preserve the BCCTP.

## THE BREAST CANCER ENVIRONMENTAL RESEARCH ACT (BCERA)

On May 21, 2008, in the Rayburn House Office Building, NBCC President, Fran Visco, and singer-songwriter Sheryl Crow testified before the House Energy and Commerce's Subcommittee on Health for passage of the Breast Cancer Environmental Research Act (BCERA).

Four months later, both the House and the Senate approved BCERA, but passed a version of the bill that was not the bill that had the support of NBCC, or of 287 Members of Congress and 70 Senators. The bill that ultimately was enacted into law, did not accomplish the goals set out by the NBCC-supported legislation.

NBCC believes that if the status quo remains in place at the NIH and the NCI, we will never end breast cancer. The system we proposed in the NBCC-supported Breast Cancer and Environmental Research Act would have changed that status quo, using proven, innovative approaches to the allocation of scientific resources. The legislation would have supported a new research model that would have ensured public funds were spent responsibly and strategically, moving away from the isolated research approaches followed over the past many years. Finally, the bill was intended to demonstrate to the scientific community at NIH the importance and success of models that include trained, educated advocates at all levels of decision-making.

## SHERYL CROW TESTIFIES WITH NBCC IN SUPPORT OF THE BREAST CANCER ENVIRONMENTAL TREATMENT ACT

On May 21, 2008, singer-songwriter and breast cancer survivor, Sheryl Crow testified alongside Fran Visco and Dr. L. Kim Lyerly of the Duke University Comprehensive Cancer Center to push Congress to pass the Breast Cancer and Environmental

*Continued on page 21*

## LOBBY DAY 2008

At the conclusion of the 2008 Conference, several hundred advocates converged on Capitol Hill to meet with their members of Congress. Over 40 states were represented and more than 400 meetings occurred throughout the day. NBCC's *Framework for Health Care System Guaranteeing Access to Quality Health Care for All* was a key discussion topic during these meetings, as was fiscal year 2009 funding for the Department of Defense peer-reviewed Breast Cancer Research Program.

Lobby Day concluded with a reception in the Russell Senate Office Building where NBCC honored eight lawmakers for their outstanding and effective leadership in the fight against breast cancer: Senate Majority Leader Harry Reid (D-NV); Senator Orrin Hatch (R-UT); Senator Sherrod Brown (D-OH); Senator Bernie Sanders (I-VT); Senator Arlen Specter (then R-PA); Representative Tom Davis (R-VA); Representative Judy Biggert (R-IL); and Representative Henry Waxman (D-CA).



**TOP:** NBCC awards Senator Sherrod Brown (D-OH) at the annual Congressional Awards Reception

**LEFT:** Representative Lois Capps (D-CA) returns to the Congressional Awards Reception after being inducted into the NBCC Hall of Fame in 2007

**RIGHT:** Minnesota advocates meet to discuss NBCC legislative priorities

**BOTTOM:** Advocates on the Hill walk to their Congressional appointments



Research Act. Ms. Crow worked alongside NBCC for 2 years to advance NBCC's agenda and highlight the importance of examining environmental factors as related to breast cancer.

During her testimony, Ms. Crow shared her personal connection to breast cancer and her deep understanding of the issues. "Like the vast majority of women diagnosed with breast cancer," said Ms. Crow, "I have no known risk factor, including no family history. I have no idea why I got breast cancer, or what I can say to others who want to prevent it. Here's what I do know: we need to put more resources into figuring out what the environment has to do with breast cancer. We need to do that through government funding, because there is little financial incentive for anyone else to do this research."

### Excerpts from *The Cancer Letter*



*The Senate approved, by voice vote on September 27th, a bill to authorize \$40 million for NIH-funded research on the causes of breast cancer. The bill passed the House on Sept. 25. The bill was intended to apply the funding model used by the Department of Defense Congressionally Directed Medical Research Programs to research on the environmental causes of breast cancer, but the bill was essentially gutted in the House.*

*The National Breast Cancer Coalition worked on the bill, the Breast Cancer and Environmental Research Act, for about eight years. "What we were trying to do was take a strategic approach and incorporate a new model into NIH based in part on the DOD program and do something innovative at NIH and show this new model can work," NBCC President Fran Visco said to *The Cancer Letter*. "The approach set forth in the original draft of the Breast Cancer and Environmental Research Act would have been a step toward a new direction at NIH."*

## BREAST CANCER CAUCUS & VOTER PLEDGE



In August, NBCC launched the Breast Cancer Caucus—a non-partisan blog aimed to inform the public on important issues related to health care reform and the Presidential election held in November of 2008. In addition, NBCC created a Voter Pledge to encourage men and women to consider the candidates' positions on NBCC's legislative and public policy priorities prior to Election Day.

An excerpt from the inaugural Breast Cancer Caucus blog post:

*At NBCC we pride ourselves on doing our homework. We look closely at public policy to really understand what it means for breast cancer survivors, their families, and everyone who wants to avoid a diagnosis of breast cancer. We pick our battles carefully... and then we're relentless until we succeed.*

*The future of breast cancer will be shaped in large part by the upcoming presidential election. Women have a one in eight lifetime risk of being diagnosed with breast cancer. **In 2008 alone, 250,000 women will be diagnosed and nearly 40,000 women will die from the disease.** Please join us in the fight to eradicate breast cancer by signing our **Voter Pledge**. By doing so, you proclaim that you will consider the candidates' positions on NBCC's legislative and public policy priorities before casting your vote in the general election. Our goal is collect a quarter million pledges to honor the 250,000 women who will be diagnosed with breast cancer this year. You may sign the pledge in honor or memory of a person close to you. In addition, if you have your own website or blog, you can help by adding our Voter Pledge widget to your page and collecting more signatures.*

*Thank you for all you do to support NBCC and help us end this disease forever.*

# YEAR IN PHOTOGRAPHS



**TOP LEFT:** Dr. Otis Webb Brawley delivers his presentation during the Breast Cancer Research: *Expectations vs. Reality* plenary at the Advocacy Training Conference

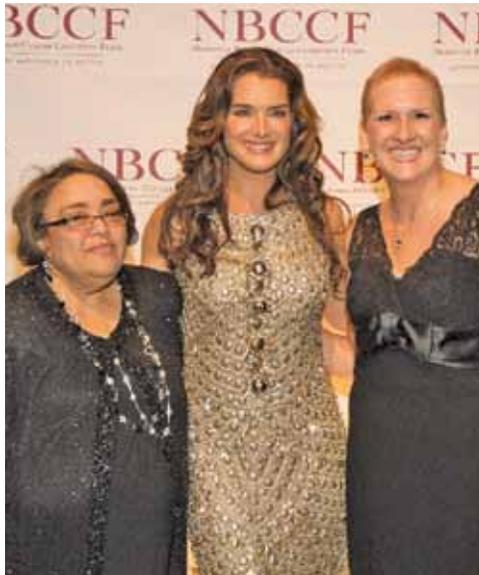


**TOP RIGHT:** Senate Majority Leader Harry Reid (D-NV) accepts NBCC Congressional Award

**BOTTOM LEFT:** Abigail Trafford of *The Washington Post* moderates the *So What's New in Breast Cancer? Plenary*, April 2008

**BOTTOM RIGHT:** Advocates pose in front of the Capitol building on Lobby Day





**TOP LEFT:** Wo(men) Who Get it Right® Advocacy Award recipient, Brooke Shields with Wo(men) Who Get it Right Grassroots Advocacy Award recipients, Jackie Hill of Omaha, Nebraska and Linda Croucher of Cincinnati, Ohio

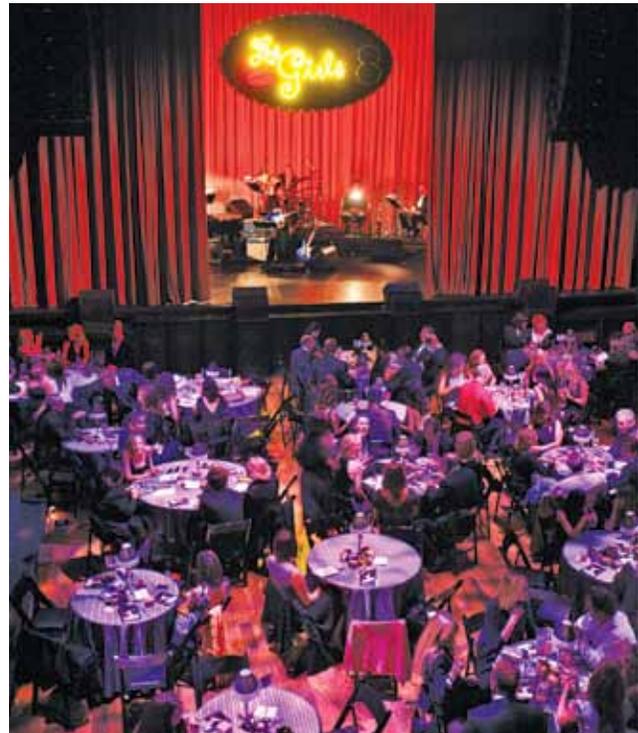
**TOP RIGHT:** New York Gala 2008 held at Cipriani 42nd St.

**BOTTOM LEFT:** Alison Krauss performs

**BOTTOM RIGHT:** Brooke Shields, former President Bill Clinton and Fran Visco with Leadership Award recipient, Sumner Redstone



# YEAR IN PHOTOGRAPHS



**TOP LEFT:** Cabaret performance by Tracee Ellis Ross at Les Girls 8

**TOP RIGHT:** Les Girls 8 held October 2008 in Los Angeles, CA

**MIDDLE LEFT:** Cindy Pearson speaks out at the Annual Advocacy Training Conference

**BOTTOM LEFT:** Adelson Galleries private showing of a Mary Cassatt exhibition to benefit NBCC Fund, New York, April 2008

**BOTTOM RIGHT:** Living Proof Premiere, Washington, D.C., September 2008





**TOP LEFT:** Representative Judy Biggert (R-IL) accepts NBCC Congressional Award

**TOP RIGHT:** Advocates applaud a strike at the Women with Balls® Advocate Bowling Challenge

**BOTTOM LEFT:** Advocates celebrate and dance at the Annual Conference Reception

**BOTTOM RIGHT:** 3rd Annual Corporate Bowling Challenge and Silent Auction



## 2008 FINANCIALS

In 2008, NBCC continued to build a strong financial foundation to support our work for both current and upcoming years.

Thanks to our donors and supporters, the total revenue raised to support the National Breast Cancer Coalition Fund was over \$10 million. More than \$4 million of that support was a commitment for funding in 2009 and 2010, allowing the organization to create new programs and expand current programs in our mission to eradicate breast cancer.

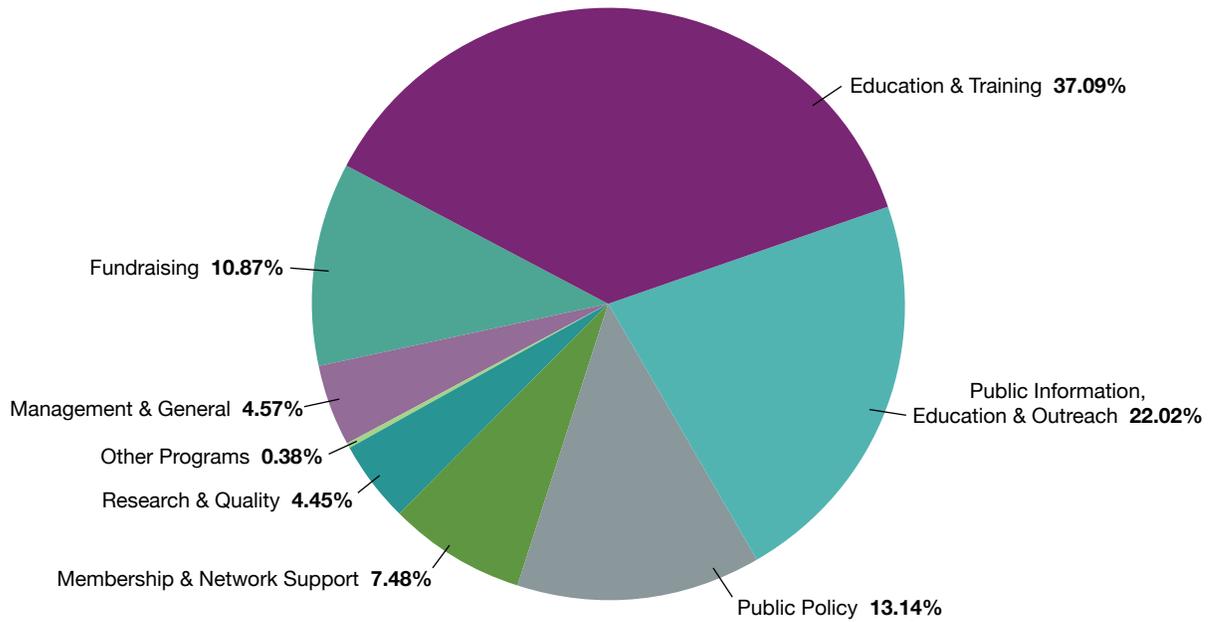
In 2008, over \$5 million, or nearly 85% of total expenses, was invested in program activities such as education, training, research and public policy. This figure represents a growth of roughly 25% over 2007, which translates into further education of advocates, more support of member organizations, more frequent convening of innovative leaders in breast cancer, more impact on the international stage and stronger leadership in healthcare reform.

NBCC's net assets as of December 31, 2008 were \$6.7 million, ensuring a secure expansion and continued investment in our mission.

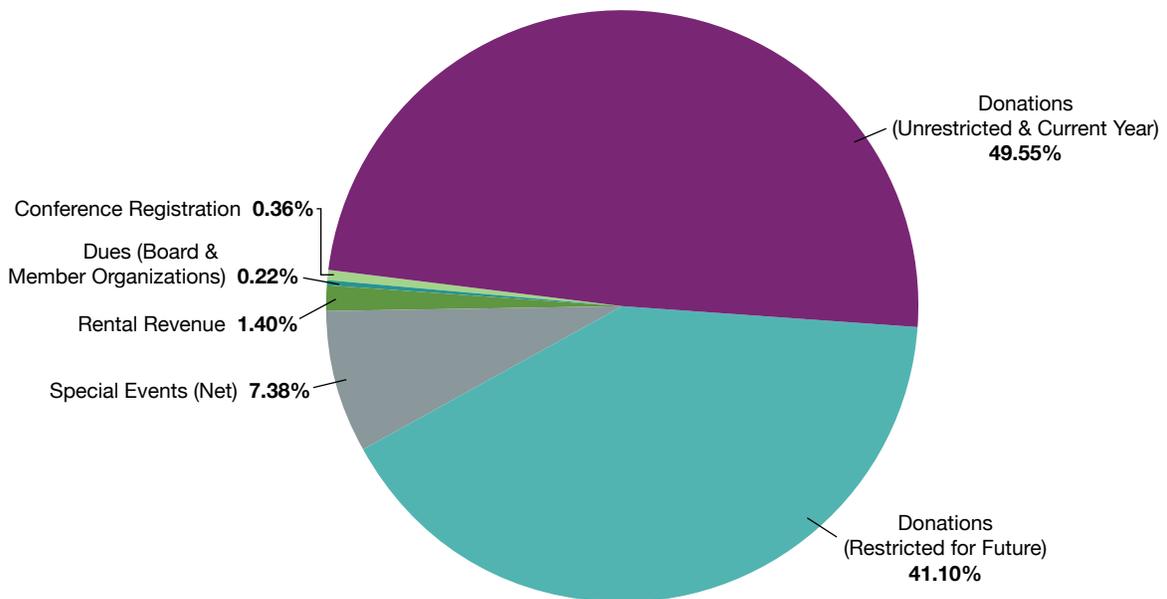
Your contributions enable us to continue important work to end breast cancer once and for all. We are grateful to each and every one of you who supported us in 2008.

<b>ASSETS</b>	
Cash & Cash Equivalents	339,718
Accounts Receivable	4,681,754
Prepaid Expenses	84,691
Investments	2,435,548
Property & Equipment (net)	166,248
Deposits	38,167
<b>TOTAL ASSETS</b>	<b>7,746,126</b>
<b>LIABILITIES</b>	
<b>TOTAL LIABILITIES</b>	<b>1,044,077</b>
<b>NET ASSETS</b>	
Unrestricted	516,652
Temporarily Restricted	6,185,397
<b>TOTAL NET ASSETS</b>	<b>6,702,049</b>
<b>TOTAL LIABILITIES &amp; NET ASSETS</b>	<b>7,746,126</b>

**2008 Expenses: \$6,040,975**



**2008 Public Support & Other Revenue: \$10,669,467**



# DONORS

## CORPORATE, FOUNDATION & ORGANIZATION DONORS

### \$1,500,000 and Above

Avon Foundation for Women  
Breast Cancer Fund of National Philanthropic Trust

### \$500,000 to \$1,499,999

Entertainment Industry Foundation  
Genentech, Inc.  
Joyce and Irving Goldman Family Foundation  
Vance Wall Foundation

### \$250,000 to \$499,999

sanofi-aventis US, Inc.

### \$100,000 to \$249,999

Breast Cancer International Research Group  
Sumner M. Redstone Charitable Foundation

### \$50,000 to \$99,999

Amgen  
Barnes and Noble College Booksellers, Inc  
CBS Studios, Inc  
Conde Nast Publications  
Lilly USA, LLC  
The News Corporation Foundation  
Revlon Group Foundation Inc  
Universal Music Group, Inc  
Viacom International, Inc.

### \$25,000 to \$49,999

Adelson Galleries, Inc.  
Bristol-Myers Squibb Company  
Edge Entertainment, Inc  
Genomic Health, Inc.  
GlaxoSmithKline  
Novartis Oncology  
Skadden, Arps, Slate, Meagher & Flom LLP

### \$10,000 to \$24,999

Abbott Laboratories  
America's Health Insurance Plans  
AOL  
Arnell Group, Ltd.  
Betsey Johnson  
The Broder Foundation  
California Teachers Association  
Carat USA  
Casey 1995 Trust  
The Clark Charitable Foundation  
DirecTV  
Display Producers Inc.  
Endeavor Marketing  
Gucci  
The Hargrove Pierce Foundation  
Innovative Skincare  
Jewish Community Foundation of Los Angeles  
The John Mahoney Foundation  
The Karan-Weiss Foundation  
Linear Technology Corporation  
Mellam Family Foundation  
PriceWaterhouseCoopers  
Translational Oncology Research  
International, Inc.  
Ziffren, Brittenham, Branca, Fischer, Gilbert-Lurie, Stiffelman,  
Cook, Johnson, Lande & Wolfe

### \$5,000 to \$9,999

Ayco Charitable Foundation  
Barkley Evergreen & Partners, Inc  
Barr Laboratories  
Brown-Forman Corporation  
C. B. Coleman & Joan F. Coleman Charitable Foundation  
California Community Foundation  
David and Susan Bershad Foundation, Inc.  
Doctoroff Family Foundation  
Endeavor Talent Agency  
Hill and Knowlton, Inc.

Hologic, Inc.  
Jewish Community Foundation  
Levitan Family Trust  
Sony Pictures Entertainment, Inc.  
The Glen and Mary Ann Charles Family Foundation  
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*Thank you  
to our donors!*

# 2008 PRESIDENT COUNCIL MEMBERS

The President's Council is a national network of likeminded women and men who provide leadership and financial support to the National Breast Cancer Coalition Fund in our mission to eradicate breast cancer. Our President's Council members are key ambassadors, reaching into their own communities and networks on our behalf. We recognize these individuals for their generous support of \$1,000 or more in 2008.

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		Ann C. Yahner
		Kathleen and Stanley Zeitz
		Laura Ziskin

# OUR VALUES

These values are the foundation of the National Breast Cancer Coalition and Fund. They define who we are and how we work. Our decisions are grounded in these values; they guide all our relationships.

We live them every day.

## **Urgent**

We must end breast cancer now.

## **Tenacious**

Until breast cancer is eradicated, we will never give up and we will never back down.

## **Questioning**

We challenge the status quo, view everything with a critical eye and analyze all information before we act.

## **Courageous**

We ask hard questions and make difficult decisions. When the evidence dictates, we reject popular or accepted thinking.

## **Informed**

We do our homework and make strategic choices based on evidence.

## **Inclusive**

We require diversity of thought, action and perspective in everything we do. We want everyone at the table.

## **Results-driven**

We focus on creating the greatest, most meaningful impact; we bring about real change.

## **Principled**

We are committed to the integrity of our mission and hold ourselves and others accountable for positions and actions taken.

## **Innovative**

We challenge ourselves and others to create new models and approaches.

## **Compassionate**

No one else should suffer.



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1101 17th St., NW, Suite 1300, Washington, DC 20036  
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