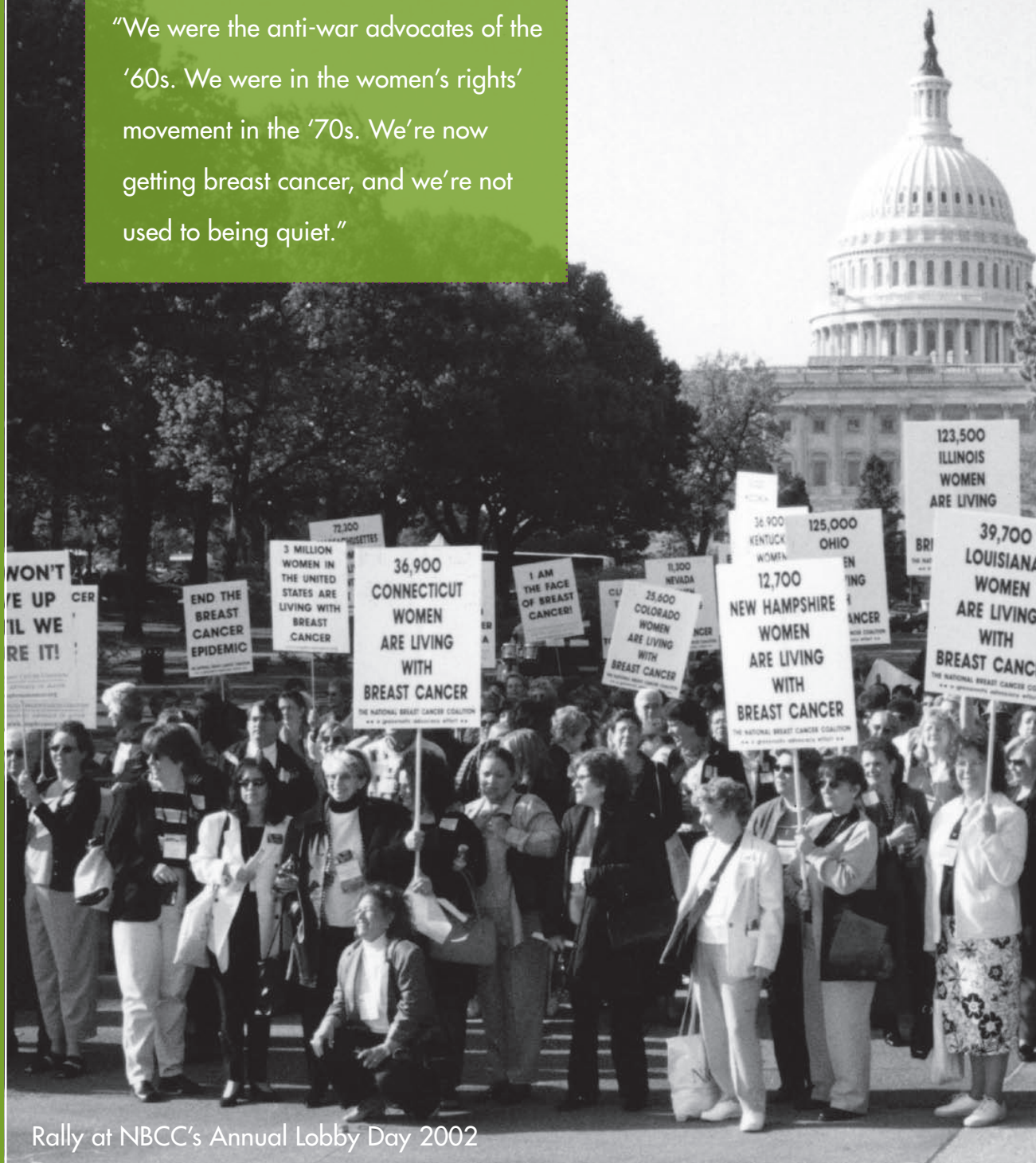



"We were the anti-war advocates of the '60s. We were in the women's rights' movement in the '70s. We're now getting breast cancer, and we're not used to being quiet."



Rally at NBCCF's Annual Lobby Day 2002

NATIONAL BREAST CANCER COALITION
NATIONAL BREAST CANCER COALITION FUND

15TH ANNIVERSARY REPORT 2006



☐ Send me membership information about the NATIONAL BREAST CANCER COALITION

Name: Christina Barajas Signature: Barajas

Address: Dear President Clinton

Age: in six years old

☐ I am a person concerned about this epidemic

Why you care:

I am a:

☐ Survivor

☐ Spouse or Partner

☐ Daughter, Son

☐ Parent, Grandparent

☐ Sister, Brother

☐ Friend, Co-Worker of someone who has been affected by this disease

☐ A person concerned about this epidemic

Send me membership information about the NATIONAL BREAST CANCER COALITION

Signature: _____

State: _____ Zip: _____

Why you care:

I am a:

☐ Survivor

☐ Spouse or Partner

☐ Daughter, Son



TABLE OF CONTENTS

From the President	1
Fifteen years of NBCCF	2
Research	5
Access and Quality	8
NBCCF Committees	9
Influence	10
Conference Sponsors	12
Events	13
NBCC	15
In the News	17
Financials	19
Corporate & Foundation Donors	21
Individual Donors	23
Board of Directors	25

FROM THE PRESIDENT



We are here. And we are still strong and fighting.

In 2006, the National Breast Cancer Coalition and National Breast Cancer Coalition Fund marked our 15-year anniversary. That milestone gave us an opportunity to celebrate our breast cancer advocacy work and to assess our vision for the future. While it was unrealistic to do so, fifteen years ago we had hoped that there would be no need for our advocacy by now. We quickly realized we were wrong. While fifteen years may not be long in the non-profit world, it is too long when lives are at stake. That belief lends urgency and substance to our work and recognition that we have no time for “kinder-gentler” advocacy. Then and now, we have to constantly focus on the difficult issues that would make a real difference each and every year until we end breast cancer.

Since our inception in 1991, we have revolutionized the advocate role in breast cancer research, access to care, public policy, and the overall decision-making process. No longer silent partners, women and men with breast cancer, their friends and families and the breast cancer grassroots movement have clearly stepped forward to take the lead and guide and shape the search for both a cause and a cure. As you can see from this report, NBCCF continues to have a significant impact on all aspects of breast cancer.

In 2006, we continued to play a prominent role in a number of noteworthy clinical trials, and successfully brought our particular brand of informed advocacy to new arenas such as biomarker research. Through Project LEAD® we trained more advocates, now more than 1200, in research, science, and quality care, exponentially expanding our influence. We constantly hear from our graduates about the ways they have applied their NBCC learning in their communities. And we made progress on one of our key priorities, expanding quality health care for all.

On Capitol Hill, the Coalition renewed our push for the Breast Cancer and Environmental Research Act. And we once again shepherded the Department of Defense Breast Cancer Research Program through the annual appropriations process, bringing the total funding since our inception to nearly \$2 billion for the worldwide research community.

As always, whether through events like the New York Gala and our Cabaret in Los Angeles, or through individual gifts and contributions, your support made this work possible. Suffice it to say that without your help, none of this would be possible.

Fran Visco

A handwritten signature in dark ink that reads "Fran Visco". The script is fluid and cursive, with a large, stylized 'F' and 'V'.

FIFTEEN YEARS OF NBCC/F



1991 A small group of women decide that the breast cancer movement needs a powerful advocacy arm with a single mission: to eradicate breast cancer. NBCC is born. Our first campaign, *Do The Write Thing*, delivers 600,000 letters to the president and Congress and spurs a dramatic increase in federal funding for breast cancer research.

1992 Research hearings held by NBCC and attended by prominent scientists establish funding needs for breast cancer research. NBCC's successful *\$300 Million More Campaign* is launched, resulting in a four-fold increase in federal funding.

1993 NBCC spearheads the creation of a peer-reviewed breast cancer research program within the U.S. Department of Defense. NBCC successfully establishes, protects and builds this program for over a decade, which has directed more than \$2 billion to breast cancer research worldwide.

1993 - 1994 In response to NBCC's *2.6 Million Campaign*, President Clinton launches a National Action Plan on Breast Cancer. NBCC members assume leadership positions and help identify the Plan's priority areas.

1995 Project LEAD®, NBCCF's innovative science program for breast cancer advocates, is created. LEAD graduates go on to participate in the design of breast cancer research around the country and the world.

1996 NBCC hosts the nation's first Breast Cancer Think Tank, the Aspen Project. This innovative forum becomes a catalyst for many of NBCC's groundbreaking programs.

1997 NBCCF hosts the first World Conference on Breast Cancer Advocacy in Brussels, Belgium. The program provided activists with up-to-date information on breast cancer research and strategies to become involved in breast cancer decisionmaking.

1998 A new model of collaboration is born when NBCC partners with researchers in the first targeted therapies in breast cancer. This dramatically shortens the time from research to approval.

1999 NBCC hosts a Breast Cancer Quality Care Summit to develop a patient-centered, science-based vision of care. NBCCF's Guide to Quality Breast Cancer Care provides advice for women facing breast cancer and a blueprint for quality care advocates seeking to improve the health care system.

2000 After many years of relentless NBCC grassroots advocacy, Congress enacts the Breast and Cervical Cancer Treatment Act. The Act provides matching Medicaid funds to states so low-income women diagnosed with breast or cervical cancer through the federal screening program get coverage for treatment.

2001 A Clinical Trials Summit, hosted by NBCC, brings advocates and multi-disciplinary experts together. The participants discuss potential improvements in the clinical trials system to find more effective treatments for breast cancer in a timely manner.





2002 *Not Just Ribbons* national campaign shifts focus away from “awareness” to substantive policy issues such as genetic discrimination, access to cancer therapies, breast cancer and the environment and increased funding.

2003 As a testament to the power of NBCC advocates, NBCC is named one of the top 25 most influential groups in national health policy in a University of Chicago survey.

2004 NBCCF offers the first international Project LEAD® course in Madrid, Spain, attended by 34 students from 20 countries.

2005 NBCCF brings together more than 50 leading researchers, government representatives and breast cancer advocates for the Strategic Consensus Conference on Biomarker research. Former President Bill Clinton announces the formation of the Virginia Clinton Kelley Fund at NBCCF in memory of his mother.

2006 NBCCF launches the Best Practices in Breast Cancer Advocacy Awards program, convenes a Drug Pricing Workshop, and at our annual Advocacy Training Conference, begins a year-long celebration of our 15 years.

RESEARCH

SINCE OUR FOUNDING, THE NATIONAL BREAST CANCER COALITION FUND has recruited and trained consumer advocates whose fresh insights changed breast cancer research. We have new ideas and passionate leadership that have led to concrete results in the breast cancer research arena. Our commitment to evidence-based medicine is our hallmark, from groundbreaking Project LEAD® training to in-depth participation in all aspects of important clinical trials.

Clinical Trials

In 2006, NBCCF continued its involvement with TAILORx, a large-scale trial studying whether women with early-stage breast cancer that have certain genomic characteristics can forego chemotherapy. The trial will eventually enroll more than 10,000 patients from 900 sites in the United States and overseas. Our representatives have been involved in trial design and oversight as members of the Steering and Data Monitoring Committees. We are also using our extensive outreach network to assist in recruiting women for this crucial study.

In November, the U.S. Food and Drug Administration (FDA) approved trastuzumab as a treatment for HER2-positive, node-positive breast cancer in the adjuvant setting. NBCCF played an important role in this achievement, partnering with the Breast Cancer International Research Group on a large international clinical trial (BCIRG 006) that studied the combination of Herceptin® with two distinct chemotherapy regimens, one of which did not include an anthracycline in the chemotherapy mix. In prior years, NBCCF played a critical role in collaboration with Dr. Dennis Slamon and Genentech in the successful clinical trials that led to the initial approval of this drug in the metastatic setting.

Drug Pricing Workshop

In September, NBCCF convened a focused workshop in Chicago on the complex question of how society should guarantee access to effective therapies, while at the same time encouraging investment in innovative research and development. Workshop participants included 19 key stakeholders from government, industry and the consumer communities, scholars, clinicians, policy analysts and ethicists. This meeting, made possible thanks to a generous grant from the Breast Cancer Fund of the National Philanthropic Trust, was a key step toward informing our work in the areas of research and access to quality health care for all.

Shaping the future of biomarker research in breast cancer to ensure clinical relevance

M. Carolina Hinesrosa, MA, MPH¹, Kay Dickerson, PhD², Pamela Klein, MD³, Musa Mayer, MS⁴, Karin Noss⁵,
Dennis Slamon, MD, PhD⁶, George Sledge, MD⁷, Frances M. Visco, JD¹

¹National Breast Cancer Coalition Fund, ²Johns Hopkins Bloomberg School of Public Health, ³Genentech, Inc., ⁴Advancetech, Inc., ⁵Virginia Breast Cancer Coalition, ⁶UCLA Jonsson Comprehensive Cancer Center, ⁷Indiana University School of Medicine.

Abstract

Each year, more than 300,000 women are diagnosed with invasive breast cancer in the United States. Although the use of biomarkers has the potential to guide preventive interventions and to improve survival through targeted therapies, and quality of life through decreased over-treatment, there have been few successes and many disappointments. In November 2005, the National Breast Cancer Coalition Fund (NBCCF) convened a conference as part of a biomarker development process to address the need for a multi-stakeholder approach to biomarker research. The conference, clinicians, basic researchers, industry representatives, and regulators who served on the consensus panel developed five general principles that serve as the framework for our consensus priorities and 18 specific recommendations.

Process

The Strategic Consensus Conference on Biomarker Research in Breast Cancer convened on November 15-16, 2005 to address the question: *What is needed to ensure that biomarker research effectively answers clinically relevant questions about breast cancer?*

Conference goals:

- Identify gaps and develop strategies in the most important strategic steps necessary to ensure that basic biomarker research translated into useful and valid clinical applications as quickly as possible.
- Recommend a viable model for strategic consensus building that is rigorous and led by consumer advocates and advocates.
- Monitor conference participants and others to implement a strategic plan developed through the consensus process.

Consensus process:

- NBCCF conducted interviews with leaders from diverse disciplines to focus the content of the workshop and set a research effort to identify lessons learned from previous biomarker development efforts.
- A multidisciplinary working subcommittee provided advice on the conference agenda and selection of fifty experts representing diverse perspectives.
- The panel divided into three groups to focus on the following specific biomarker use settings:
 - Panel A: Determination of use and assessing
 - Panel B: Differential diagnosis, prognosis, and predictors
 - Panel C: Monitoring disease course
- Each group had two five sessions, with each session devoted to a separate question:
 - Session 1: How should we define clinical utility in the context of biomarkers in breast cancer?
 - Session 2: How should we define clinical utility in the context of biomarkers in breast cancer?
 - Session 3: How should we define clinical utility in the context of biomarkers in breast cancer?
 - Session 4: How should we define clinical utility in the context of biomarkers in breast cancer?
 - Session 5: How should we define clinical utility in the context of biomarkers in breast cancer?
- Session 6: Which recommendations are best for validating biomarkers?

Outcomes

Biomarker: any measurable cellular, subcellular, or humoral factor that demonstrates the presence of malignancy or malignant potential, or predicts tumor behavior, prognosis, or response to treatment.

GENERAL PRINCIPLES

- Research on biomarkers and their clinical use must be patient centered.
- Biomarker research must aim to substantially improve patient outcomes by accurately identifying those likely to benefit from specific interventions and sparing those who will probably not benefit from these interventions.
- Research on biomarkers must be conducted in an environment of social responsibility in which resources are shared as part of a social network.
- The research community must foster and encourage innovative ideas and approaches toward making substantial improvements in patient care.
- Stakeholders must adopt and abide by agreed-upon standards and guidelines for conducting research, reporting results, and the clinical use of biomarkers.

CONSENSUS PRIORITIES AND RECOMMENDATIONS

- PRIORITY 1:** Develop and adopt standards and guidelines for all different stages of the "search to baseline" continuum to ensure that only biomarkers with clinical utility make their way into routine clinical practice.
- Incorporate the best components of drug development to guide the development and validation of biomarker assays.
 - Expand and encourage adoption of guidelines for the publication of biomarker study results.
 - Adopt and enforce common guidelines for clinical use of biomarkers and ensure their implementation.
 - Adopt and enforce common clinical methodologies for biomarker measurement and reporting.
- PRIORITY 2:** Improve access to biological specimens including associated clinical data and research study information.
- Establish a central registry of assays and new specimens.
 - Facilitate the use of biological specimens.
 - Ensure that additional data are collected even after a biomarker appears to have been validated.
 - Improve access to information in biomarker research studies.
- PRIORITY 3:** Strengthen the role of regulatory agencies, particularly the FDA, in ensuring the responsible and independent clinical use of biomarkers.
- Develop and enforce common guidelines for the publication of biomarker study results.
 - Expand and encourage adoption of guidelines for the publication of biomarker study results.
 - Adopt and enforce common clinical methodologies for biomarker measurement and reporting.
 - Adopt and enforce common clinical methodologies for biomarker measurement and reporting.
- PRIORITY 4:** Promote synergistic collaboration across research disciplines and among industry, academia, and consumer advocates.
- Development of biomarker assays and new therapies must be in tandem.
 - Encourage interdisciplinary collaboration to develop biomarker research studies.
 - Establish all stakeholders, including clinicians and consumers, in all aspects of biomarker research and use.
 - Address the public about evidence-based use of biomarkers and the role of regulatory agencies with regard to biomarker research.
 - Establish mechanisms to ensure ongoing.
 - Establish priority review for biomarkers that are evidence based and meeting ongoing.
- PRIORITY 5:** Adopt legislation to protect patients against discrimination on the basis of biomarker information.
- Adopt and enforce common clinical methodologies for biomarker measurement and reporting.
 - Adopt and enforce common clinical methodologies for biomarker measurement and reporting.
 - Adopt and enforce common clinical methodologies for biomarker measurement and reporting.
 - Adopt and enforce common clinical methodologies for biomarker measurement and reporting.

Conclusions

NBCCF believes that the consensus conference was successful at achieving two of its three intended goals: developing consensus among key stakeholders and demonstrating a rigorous, consumer-led model for strategic consensus building. NBCCF will work diligently with other stakeholder groups to achieve the third goal of mobilization to implement the strategic priorities resulting from the consensus process.

The six recommendations ranked most highly by panel members, including their proposed timeline for implementation, are as follows:

- Incorporate the best components of drug development to guide the development and validation of biomarker assays (short term).
 - Clear guidance from appropriate regulatory agency is needed.
 - Drug development pathway serves as reference but process must be tailored to the particular needs of biomarker development.
- Establish a centralized registry for biological specimens and clinical data that are collected during trials conducted by industry, government, and academic institutions. Develop a unified system for the collection of breast cancer treatment and outcomes data (short to mid term).
 - Central registry using standardized system for collection of treatment and outcomes data.
 - Clear and transparent rules to prioritize use of tissue and serum.
 - Federal claims must be made available for establishment and maintenance of central registry.
- Development of biomarker assays and new therapies must be in tandem (immediate to short term).
 - Co-development of therapeutics and diagnostic assays essential to delivery on promise of biomarker research.
 - Synergistic collaboration of academic, industry, regulatory agencies, consumer advocates is needed.
 - Improvements for co-development must be coordinated and re-aligned.
- Develop standards to encompass methodologies for biomarker measurement and reporting in the clinical (short to mid term).
 - Optimal assays for biomarker measurement must be determined.
 - Best methods for biomarker reporting in pathology reports must be standardized.
- Revise and streamline the consent process for collecting and using specimens for biomarker studies (immediate to short term).
 - Consent process must focus on revealing information needs of potential research participants.
- Expand and ensure the adoption of guidelines for the publication of biomarker study results (immediate).

Acknowledgements

We thank The Hugh Foundation, The Virginia Cancer Policy Fund, Perseus Ventures, The David Dock Foundation, and the many individuals who participated as consensus panel co-chairs, group co-chairs, facilitators, and participants in the Strategic Consensus Conference on Biomarker Research in Breast Cancer.

NATIONAL BREAST CANCER COALITION FUND
presenting advocacy in action

An abstract of NBCCF's biomarker research report displayed at the San Antonio Breast Cancer Symposium. [Click to enlarge.](#)

Biomarker Consensus Report

In December we presented our report "Shaping the Future of Biomarker Research in Breast Cancer to Ensure Clinical Relevance" during a poster session at the 29th Annual San Antonio Breast Cancer Symposium. The report documents the recommendations of a multi-stakeholder Strategic Consensus Conference convened by NBCCF, and outlines specific recommendations to guide the future of biomarker research and make sure that the focus truly is on saving women's lives.

Beyond the Headlines

When research results are covered by the media, the issues are often too complex, and hype, errors and exaggeration can get in the way. This is why NBCCF keeps a close eye on breast cancer news, providing analysis and commentary to explain to breast cancer survivors and other interested members of the public what the research actually means, and calling for answers to the unanswered questions raised by these studies.

NBCCF has provided analysis of the following news stories and studies in 2006:

[California EPA Air Resources Board Concludes that Environmental Tobacco Smoke Causes Breast Cancer](#)

[Report Finds the Rate of New Breast Cancer Cases Diagnosed in the U.S. Has Stabilized](#)

[Highlights from the 2006 ASCO Annual Conference](#)

[Study Finds Young African American Women More Likely to Develop Basal-Like Type of Breast Cancer](#)

[NBCC - The STAR Trial: Raloxifene versus Tamoxifen for Breast Cancer Risk Reduction](#)

[Letrozole \(Femara®\) versus Tamoxifen \(Nolvadex®\) in the Adjuvant Setting: The BIG 1-98 Study](#)

[FinHer Study Finds That Short Course of Herceptin Might Be Effective Against Breast Cancer Recurrence and Also Limit Heart Damage](#)

[Study Finds Low Fat Diet Does Not Decrease Breast Cancer Risk](#)

[NBCC - AHRQ's Report Finds That Imaging Tests Cannot Reliably Be Used To Diagnose](#)

[Breast Cancer After An Abnormal Mammogram](#)

One notable study we examined in 2006 was a report co-released by the National Cancer Institute (NCI), American Cancer Society (ACS), Centers for Disease Control and Prevention (CDC) and the North American Association of Central Cancer Registries (NAACCR). The report indicated preliminary findings of a stabilization in the rate of breast cancer cases in the United States for the first time

NBCCF provides analysis and commentary to explain what the research actually means, and calls for answers to the questions raised by these studies.

since 1980. A later study presented at the San Antonio Breast Cancer Symposium suggested that a sharp decline in the use of hormone replacement therapy since 2002 explained a steep reduction in the incidence of certain types of breast cancer. In our analyses of these studies, NBCCF cautioned against rushing to the conclusion that this will result in fewer diagnoses or deaths over the long-term. As much as we would like this to be the case, this data may in fact reflect a delay in diagnosis.

In the area of diet and breast cancer, The Archives of Internal Medicine published a study which indicated that greater red meat consumption was associated with an increased risk of a certain type of breast cancer (hormone receptor positive) in younger, premenopausal women. This is an intriguing finding that warrants more study. NBCCF analyzed this study and explained the importance of determining the reason — for instance the meat's preparation or any hormones in the cattle feed. The study's author was invited to present her work at the 2007 Annual Advocacy Training Conference. Another diet study carried out as part of the Women's Health Initiative and published in the *Journal of the American Medical Association* found no overall decrease in breast cancer incidence among postmenopausal women who reduced their total fat intake and increased their consumption of fruits and vegetables compared to women who did not change their diet. NBCCF challenged media reports suggesting that the results of this study might be positive, because in fact the results were not statistically significant.



SINCE OUR FOUNDING 15 YEARS AGO, THE NATIONAL BREAST CANCER COALITION FUND has worked to be sure that all women and men diagnosed with breast cancer understand and impact systems of health care and receive access to the treatment they need, and to the information necessary for informed choices. Early on, we conceived of and led passage of the Breast and Cervical Cancer Treatment Act in 2000, and each year we push for federal funding for this important system of care for underserved women.

Our health care access work is based on one overarching principle: comprehensive, quality health care is a basic human right. We will fight for a system of coverage that reflects the core values we adopted in 2003: access, choice, respect, information, accountability and improvement. Our goal is guaranteed access to quality health care for all.

In 2006, our board of directors began to define a system of health care coverage that reflects these core values. This will be our blueprint to educate and mobilize our network of grassroots advocates to pursue health care reform.

This work is not easy. As a coalition with hundreds of member organizations, we reflect the diversity and complexity that is breast cancer in the United States. Our board members bring the voices of a wide range of national, state and community-based member organizations, including African American Women in Touch (Ind.), SHARE (N.Y.), Women of Color (Calif.), Nueva Vida (Latina Organization of Metropolitan Washington), the Mautner Project for Lesbians with Cancer, The Georgia Breast Cancer Coalition Fund, California Breast Cancer Organizations (CABCO) and many others.

Our health care access work is based on one overarching principle: comprehensive, quality health care is a basic human right.

Ours is a groundbreaking effort—developing a comprehensive plan for health care reform from the perspective of informed consumers. No other patient advocacy organization is better suited than NBCCF to take on this challenge. We have created a broadly diverse, experienced and well-educated group of health care consumers who embrace the principles of public health and evidence-based health care.

Once our plan is drafted, we will hold a stakeholder meeting in the fall of 2007 to get input from an even broader audience on its economic, political and operational feasibility.

The final result will be ready prior to the 2008 presidential primaries so that our advocates across the nation can probe the candidates and educate them on our key issues.

This is an exciting process, and with our successful track record of training and mobilizing consumer advocates to effect change, we are hopeful that it will have far-reaching outcomes.

We are building on a history of achievement that has enabled us to impact the national research agenda and increase access for the underserved.

NBCCF in Action: A Sampling

Association of American Medical Colleges Task Force on Conflicts of Interest in Clinical Research
 Breast Cancer International Research Group Member of Independent Data Monitoring Board
 Breast Cancer International Research Group Scientific Advisory Board
 Department of Defense Breast Cancer Research Program Integration Panel
 Institute of Medicine Clinical Research Roundtable
 Institute of Medicine Committee on Developing Technologies for the Early Detection of Breast Cancer
 Institute of Medicine Committee on Improvements to MQSA
 Institute of Medicine Institutional Review Board Committee
 Institute of Medicine Roundtable on Evidence-Based Medicine
 National Action Plan on Breast Cancer Steering Committee
 National Action Plan on Breast Cancer Consumer Involvement Committee
 National Cancer Advisory Board
 National Cancer Policy Board
 National Quality Forum, Breast Cancer Technical Panel
 National Institute of Environmental Health Sciences Public Interest Committee
 Oversight Body, American Medical Association Ethical Force
 President's Cancer Panel
 Working Group, Breast Cancer and Environment Research Centers

INFLUENCE



Attendees at the Advocacy Training Conference



Former Speaker of the House Newt Gingrich at the Advocacy Training Conference



PBS' Susan Dentzer (left), moderating a discussion with Fran Visco and Susan Hester at the Advocacy Training Conference

Training Breast Cancer Advocates to Challenge, Question and Lead

The National Breast Cancer Coalition Fund is recognized within the scientific community as an organization of trained and vocal consumers, knowledgeable about issues of importance to people who care about breast cancer. Through our pioneering science training course Project LEAD®, our wide-ranging participation on national committees (from the Institute of Medicine Roundtable on Evidence-Based Medicine to the American Medical Association's Ethical Force Committee), our public policy program and our annual Advocacy Training Conference, NBCCF's influence is broad, deep, and continues to have meaningful impact.

Project LEAD®

"I see LEAD graduates everywhere: at the DOD grant reviews; as authors and presenters of high quality work; and in other courses around the world in which we are participants...Over a ten-year period Project LEAD has remained dynamic and responsive to changes in the scientific and cultural environment."

– Kay Dickersin, PhD

Johns Hopkins University, Project LEAD Faculty Member

During 2006, the number of Project LEAD graduates grew by 117, bringing the total to more than 1200. We offered the core course in Houston and Washington, D.C. and held a Clinical Trials Project LEAD® in Washington as well as a Quality Care Project LEAD® in San Jose. LEAD graduates apply their new skills in an impressive variety of ways, including serving on hundreds of research panels and committees, being appointed to positions of leadership and writing and speaking out on breast cancer issues.


NBCCF is grateful to the Avon Foundation for its continued generous support of Project LEAD.

Team Leader

In 1998, the National Breast Cancer Coalition launched Team Leader, an education program training breast cancer activists to work with legislators, take on leadership responsibilities and participate in shaping public policy. Each year, we bring 80–100 women from throughout the United States to Washington to learn about the federal legislative process and advocacy techniques as well as leadership and persuasive speaking skills. Graduates of Team Leader gain an in-depth knowledge of NBCC's legislative priorities and can use these newly acquired skills to advance policy issues within their own communities throughout the year. In 2006, 91 activists gathered to prepare for NBCC's annual Lobby Day event and other policy meetings.

Best Practices Awards

In 2006, thanks to a generous grant from the Breast Cancer Fund of the National Philanthropic Trust, NBCCF launched our Best Practices in Breast Cancer Advocacy Awards. Seven organizations demonstrating strategic, high-impact programs in quality care, access and research received \$25,000 or \$50,000 grants. The seven winning programs were the Alamo Breast Cancer Foundation, the Breast Cancer Alliance of Greater Cincinnati, the Inflammatory Breast Cancer Research Foundation, the Linda Creed Breast Cancer Foundation, the Georgia Breast Cancer Coalition Fund, the New York State Breast Cancer Network and the Rhode Island Breast Cancer Coalition. Hundreds of organizations will learn from their experience through poster presentations at the 2007 Advocacy Training Conference. [Click to see the 2006 Best Practices in Breast Cancer Advocacy Awardees.](#)



**The National Breast Cancer Coalition Fund
Congratulates The 2006 Best Practices in
Breast Cancer Advocacy Awardees**

Alamo Breast Cancer Foundation
San Antonio, Texas
For its Patient Advocate Support Program

Breast Cancer Alliance of Greater Cincinnati
Cincinnati, Ohio
For its leadership role on a Breast Cancer and Environmental Research Center, a model of consumer-researcher collaboration

Georgia Breast Cancer Coalition Fund
Atlanta, Georgia
For developing a statewide grassroots program, resulting in breast cancer legislation and publicly funded resources for low-income women

Inflammatory Breast Cancer Research Foundation
Bainbridge Island, Washington
For creating BlueBark, enabling patients to donate their tissue for research and participate in unique clinical trials

Linda Creed Breast Cancer Foundation
Philadelphia, Pennsylvania
For pioneering a unique statewide alert system, linking breast cancer activists with elected officials and researchers, advancing public policy

New York State Breast Cancer Network
Schenectady, New York
For its Annual Advocacy Day, which has trained hundreds of consumers and sensitized lawmakers to survivors' needs

The Rhode Island Breast Cancer Coalition
Covington, Rhode Island
For new strategies to address the needs of women with disabilities and promoting systemic changes that reduce barriers to quality breast cancer care

These seven outstanding programs are being recognized for moving beyond awareness to real action. Each is an example for the breast cancer advocacy community.

Nominate representatives from each program at NBCCF's 2007 Annual Advocacy Conference
To register call: (866) 640-0969
www.stopbreastcancer.org

Nominate a program for the 2007 Best Practices in Breast Cancer Advocacy Awards
Call: (800) 622-2838
bestpractices@stopbreastcancer.org

NBCCF
National Breast Cancer Coalition Fund
promotes advocacy to end
www.stopbreastcancer.org

The Best Practices in Breast Cancer Advocacy Awards are made possible by a generous grant from the Breast Cancer Fund of the National Philanthropic Trust

Best Practice Award Winners



At the 2006 Advocacy Training Conference, NBCC Executive Vice President Carolina Hinestrosa (right) moderated "Access to Quality Care" Plenary Session with panelists Jackie Judd; George Askew, MD; and Barry Straube, MD.

Annual Advocacy Training Conference

The conference theme, Beyond Ribbons to Revolution, focused on the need to move beyond awareness to coordinated, strategic action to end this disease. Over 600 women and men from nearly every state and nine countries gathered to learn, network, and launch a year-long anniversary celebration of NBCCF's 15 years of grassroots advocacy in action.

The six plenary sessions explored recent advances in breast cancer research and an array of viewpoints, from former House Speaker Newt Gingrich [now with the American Enterprise Institute] to Dr. George Askew of the Center for American Progress. There were also several new workshops and, in honor of NBCCF's 15th anniversary, a memorable luncheon discussion with Fran Visco and founding board member Susan Hester. Each recalled, with great affection and humor, some of our early struggles and paid tribute to the many NBCCF members whose commitment and determination have made a difference for breast cancer survivors everywhere. After the conference ended, advocates turned their attention to Capitol Hill, holding 410 meetings on Lobby Day with lawmakers and legislative staff.

The conference theme, Beyond Ribbons to Revolution, focused on the need to move beyond awareness to coordinated, strategic action to end this disease.

CONFERENCE SPONSORS

Principal Underwriter

The Breast Cancer Fund of the National
Philanthropic Trust

Underwriters

Bristol-Myers Squibb
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sanofi-aventis

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GlaxoSmithKline
Novartis
Roche
The Virginia Clinton Kelley Fund

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Merck and Company
Revlon Run/Walk for Women, New York
(A special fundraising event of the Entertainment
Industry Foundation)

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AstraZeneca
Barr Laboratories

Supporters

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EVENTS



STRIKE! Breast Cancer Advocate Challenge

More than 30 NBCCF advocates "on at roll" at the STRIKE! Breast Cancer Advocacy Challenge on April 29th in Washington, D.C.

San Francisco Gala

Fran Visco (left), with Sue Desmond-Hellman of Genentech at the San Francisco Gala, January 30th. Desmond-Hellman received NBCCF's Corporate Leadership Award at this festive evening featuring music and jazz performances. Bonnie Anderson was also honored with NBCCF's Survivor Advocate Award.



Los Angeles Dinner

A concert from singer/songwriter Ricki Lee Jones was the highlight of a May 17th dinner in Los Angeles, at the home of Nancy Moonves.

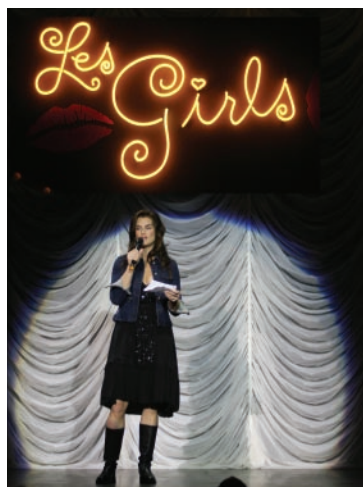
STRIKE! Breast Cancer Corporate Challenge

Members of Washington's corporate community were on hand September 19th to support NBCCF's work. STRIKE! Breast Cancer enthusiastic committee members included (left to right): Craig Muckle of Safeway; Tracey DeVaux of Booz Allen Hamilton; and Shara Hirshfield of Legal Placements, Inc. This fun-filled evening included a celebrity DJ and a silent auction.



Tea & Advocacy

Summer residents of Martha's Vineyard, including authors Rose Styron and Judy Blume, donned their fancy hats and delighted in NBCCF's first "Tea and Advocacy" celebration on August 9th. Left to right: Tea & Advocacy event planning committee members Marjorie Randell-Silver and Judi Hirshfield-Bartek; Fran Visco; event committee member Joan Kriegstein; honorary committee co-chair Rose Styron; and honorary committee member Judy Blume.



Les Girls

Brooke Shields [left photo] hosted NBCCF's Los Angeles Cabaret, Les Girls 6 on October 9th. More than a dozen stars, including Frasier's David Hyde Pierce [right photo, right] and Kelsey Grammer, and Desperate Housewives' Harriet Harris [right photo, left], donated their talents and treated everyone to an evening of song, dance and laughter.



NY Gala

Revlon's CEO, David Kennedy [left photo, left] chaired NBCCF's 11th Annual New York Gala on November 14th at Cipriani Wall Street. The elegant evening launched a

new NBCCF awards program: *Wo(men) Who Get It Right.*™ The inaugural honorees: Linda Kaplan Thaler, advertising executive [right photo, left]; Veronica Suber, NBCC advocate [right photo, right]; and Peggy Northrop, editor-in-chief, MORE Magazine [left photo, second from right.] Rene Syler, then with CBS News, [left photo, right] presented the award to Ms. Northrop.

NBCC



Rep. Lois Capps (D-CA), accepting NBCC's Annual Congressional Award

IN 1992, THE NATIONAL BREAST CANCER COALITION'S "founding mothers" demanded a significant increase in federal funding for breast cancer research. We arrived on Capitol Hill to testify, demanding \$433 million, nearly five times the budget for all cancer research that year. Told that the money wasn't there, NBCC grassroots advocates responded by bombarding congressional offices with calls, letters, faxes and visits, and we won.

Fifteen years later, breast cancer remains alive as a potent political issue. In the final hours of the 109th Congress and the first hours of the 110th, NBCC grassroots advocates helped preserve FY 2007 funding at \$127.5 billion for one of our top legislative priorities: the Department of Defense peer-reviewed Breast Cancer Research Program. NBCC's hard work was recognized by Sen. Ted Stevens (R-AK), then Chairman of the Defense Subcommittee, who said: "You women are probably the most persistent, persuasive lobbyists there are."

The Breast Cancer and Environmental Research Act (S. 757/H.R. 2231) came close to enactment in 2006. In June, the Senate Health, Education, Labor and Pensions (HELP) Committee unanimously passed the bill. With 66 Senate and 255 House co-sponsors, BCERA seemed on its way to swift passage, until Sen. Tom Coburn (R-OK) blocked it. Through the exhaustive efforts of NBCC advocates, led by field coordinators and team leaders around the country, action was taken to demand the passage of the BCERA. Many advocates used the new NBCC advocacy website, *Less Pink More Research*, to send e-mails to their elected representatives. Others fired off letters to newspapers; when Sen. Coburn responded to one appearing in *The Oklahoman*, BCERA became front-page news in that state. The 109th Congress failed to pass BCERA; however, the new congressional leadership has publicly committed to passage in 2007. As always, NBCC will hold Congress accountable.



Fran Visco, presenting the NBCC's award to Sen. Orrin Hatch (R – UT)

In addition to *Less Pink More Research*, we increased our electronic advocacy in 2006 by reintroducing the monthly e-newsletter, *Call to Action*. Two other special websites were also launched—*Get It Off Your Chest*, a vehicle for individuals to contact us about a variety of issues—and *The Golden Boob* competition, designed to shine a spotlight on efforts to exploit breast cancer for political or financial gain. The 2006 winner, announced in December: the Coalition on Abortion/Breast Cancer, for asserting that abortion leads to an increased risk of breast cancer, despite strong evidence to the contrary.

**"You women are probably the most persistent, persuasive lobbyists there are."
Sen. Ted Stevens (R-AK)**

In our 15 years, NBCC has led the way in championing responsible, meaningful advocacy. Said two staunch congressional allies, Sens. Tom Harkin (D-IA) and Orrin Hatch (R-UT): "While we're winning the war against breast cancer, the fight is far from over. When that fight ends, it will be in large part due to the unrelenting efforts of Fran Visco and NBCC."



NBCC advocates on Lobby Day with (clockwise, from with upper right photo): Sen. Hillary Rodham Clinton (D-NY); Rep. Danny Davis (D-IL); Rep. Jon Porter (R-NV); and Sen. George Voinovich (R-OH).

NBCC/F

IN THE NEWS

SPRING 2006

CANCER RESEARCH MAGAZINE

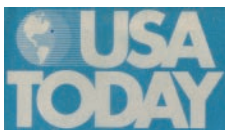
"It's disconcerting for consumers that the [estimated] range [in this study] of the benefit [for mammography screening] is so wide, because so much time and effort is put into public health messages about screening."

— *Carolina Hinestrosa, executive vice president of programs and planning*

JULY 11, 2006 USA TODAY

"These [drug] costs are out of control. We can't allow it to continue."

— *Fran Visco*



OCTOBER 1, 2006

THE NEW YORK TIMES

"Drug costs are rising so fast that some patients cannot afford the newest treatments, and access to some therapies 'is beginning to be eroded'."

— *Carolina Hinestrosa*

APRIL 18, 2006

THE CHARLIE ROSE SHOW (PBS)

"See, often the consensus that we reach in the health field is the consensus among physicians. And it really needs to be a broader group reaching consensus. I mean, patients and activists have to be part of that process. And we haven't been until recently."

— *Fran Visco*

OCTOBER 2006

MORE MAGAZINE

"You can talk all you want about early detection and targeted therapy. If everyone in this country doesn't have access to what they need—and that's quality health care—what's the point? How much money are we going to continue to put into more and more expensive interventions while fewer and fewer people have coverage?"

— *Fran Visco*

The New York Times

Decrease in Breast Cancer

To the Editor:

It is good news that breast cancer diagnoses apparently decreased in 2003 ("Reversing Trend, Big Drop Is Seen in Breast Cancer," front page, Dec. 15). It is disturbing that hormone replacement therapy may be the reason.

For years, we worried about this risk and the lack of evidence of the benefits. But doctors kept prescribing and women kept taking.

Hope that the benefits of a drug are real and the risks minimal is not sufficient; we need evidence.

The Food and Drug Administration needs to pay attention to this development. Its proposed rule regarding access to experimental drugs outside of clinical trials will worsen the problem and is a step in the wrong direction. When will we learn?

FRAN VISCO

President

National Breast Cancer Coalition

Washington, Dec. 20, 2006

OCTOBER 16, 2006

TIME MAGAZINE

"When companies make breast cancer so pink and pretty and upbeat, too many people think we're close to getting answers and that breast cancer isn't the problem it once was. That's not the right message. We may have raised awareness, but incidence rates are higher than they were 30 years ago. We don't know how to prevent or cure the disease, and more than 40,000 women still die every year."

— Fran Visco

OCTOBER 29, 2006

THE OKLAHOMAN

"The research [Breast Cancer and the Environmental Research Act] is needed because we don't know how to prevent breast cancer. We don't know how to reduce the risk of breast cancer."

— Fran Visco

NOVEMBER 14, 2006

THE WASHINGTON POST

"This [study] suggests that lifestyle, in this case diet, in early adulthood is important in potentially explaining your risk for premenopausal breast cancer."

— Carolina Hinestrosa

2006 FINANCIALS

STATEMENT OF FINANCIAL POSITION

ASSETS

	2006	2005
Cash & Cash Equivalents	\$29,401	\$98,660
Accounts Receivable	\$1,657,949	\$1,608,872
Prepaid Expenses	\$49,272	\$46,650
Investments	\$133,615	\$209,123
Property & Equipment (net)	\$103,045	\$146,651
Deposits	\$38,167	\$38,167

TOTAL ASSETS	\$2,011,449	\$2,148,123
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LIABILITIES

Current Liabilities	\$866,442	\$765,036
Other Liabilities	\$18,440	\$15,386

TOTAL LIABILITIES	\$884,882	\$780,422
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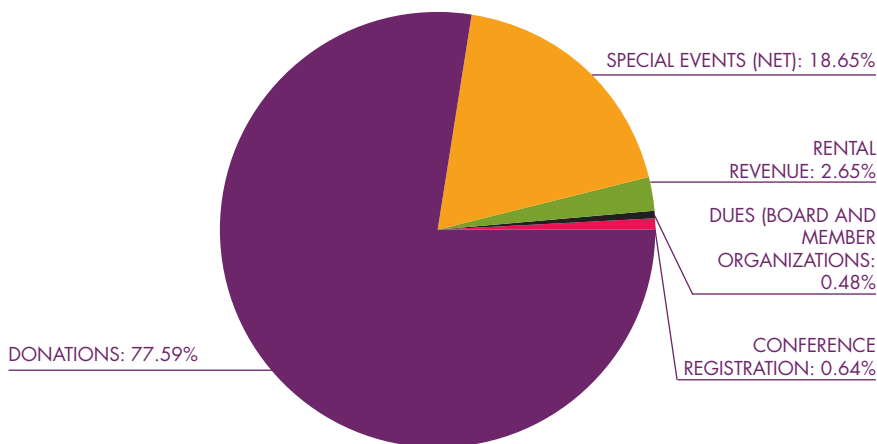
NET ASSETS

Unrestricted	(\$305,049)	\$128,508
Temporarily Restricted	\$1,431,616	\$1,239,193

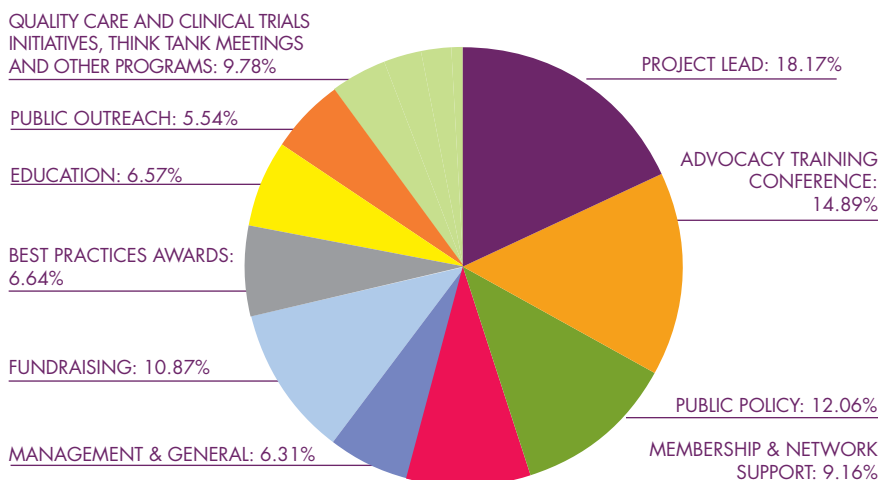
TOTAL NET ASSET	\$1,126,567	\$1,367,701
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TOTAL LIABILITIES AND NET ASSETS		\$2,148,123
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2006 PUBLIC SUPPORT AND OTHER REVENUE: \$4,830,789



2006 EXPENSES: \$5,071,923



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\$1,000,000 & Above

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LEE NATIONAL DENIM DAY

In 2006, The Entertainment Industry Foundation (EIF) selected NBCCF to join six world-renowned research institutions as recipients of Lee National Denim Day proceeds. NBCCF will use the funds to create unique web-based resources for breast cancer survivors. Fran Visco is pictured here with (left to right): Dr. Dennis Slamon, UCLA School of Medicine; Lisa Paulsen, EIF president; and Lee Jeans' Nancy White, Joe Dzialo (president), and Liz Cahill.



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Fran Visco speaking at Lee National Denim Day at Lee National Headquarters in Kansas

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The National Breast Cancer Coalition is a grassroots membership organization dedicated to ending breast cancer through the power of action and advocacy. Along with its research and education arm the National Breast Cancer Coalition Fund, the Coalition's main goals are to increase federal funding for breast cancer research; improve access to high-quality health care and breast cancer clinical trials for all women; and expand the influence of breast cancer advocates wherever breast cancer decisions are made.

Please visit www.stopbreastcancer.org for more information.



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