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# Telling the Truth and Inspiring Change: Carrying the Voices of People Affected by Breast Cancer









's mission is to carry the voices of people affected by breast cancer to inspire and compel the changes necessary to end the epidemic. We exist because far too many people have been affected by this disease. Because we remain close to our grassroots, we hear what the needs and experiences are of people affected by breast cancer, often before the medical and scientific communities do. In turn, what we hear informs the work we do.

As a matter of policy, BCA does not accept any funds from pharmaceutical, biotechnology, or chemical companies, or any other entities that profit from or contribute to the breast cancer epidemic. BCA was the first—and remains one of a few—among national breast cancer organizations to adopt such a policy. Our corporate contributions policy is key to achieving our mission and essential to telling the truth about this disease. The effectiveness of our work in public education, advocacy, and coalition building depends on our integrity and credibility, particularly in the eyes of our members and the people we serve. Whenever BCA makes a statement or takes action on a new clinical trial, a breast cancer drug, or a piece of legislation, the public can be sure it's because we believe in what we're doing, not because we've been paid to do it by a company with a vested interest.

From the top: Marilyn Zivian, Loretta Ross, Minetta Liu, and Tori Freeman were profiled in the BCA Source.

# **Highlights: 2006 Efforts and Accomplishments**

Changes at the FDA When we and other advocates received extremely short notice of the FDA's approval of silicone breast implants, BCA engaged the agency on its process of informing stakeholders of critical decisions with timely notice. Changes are being made at the FDA as a result.

**Safe Cosmetics** Fulfilling our commitment to make sure that legislation enacted to protect public health does just that, BCA began work on effective implementation of the California Safe Cosmetics Act (SB 484) with the state Department of Health Services (DHS). The act, cosponsored by BCA, requires manufacturers of cosmetics and personal care products to report to the DHS all products that contain chemicals that are known or probable carcinogens or reproductive toxins.

**Survey on Al Side Effects** BCA released the initial results from our online survey of aromatase inhibitor (Al) side effects. The report, "Side Effects Revealed: Women's Experiences with Aromatase Inhibitors," analyzed more than 600 responses to the survey. Nearly all the respondents (96 percent) reported one or more side effects, and nearly 30 percent of the respondents reported discontinuing the use of an Al, 84 percent because of intolerable side effects. In order to reach the largest audience of people affected, BCA posted the full report and comments from survey respondents online (www.bcaction.org/Alreport). BCA continues to conduct the survey in an effort to enable patients to make better treatment decisions, doctors to make more informed recommendations, and the FDA to monitor Al side effects.

**Environmental Health** BCA assumed a leading role in the California chemical policy reform working group, CHANGE—Californians for a Healthy and Green Economy. Together with our allies, we are guiding the development of policies that address public and environmental health concerns in relation to chemical manufacturing and use.

**STAR Trial Analysis** When the results of the STAR trial (Study of Tamoxifen and Raloxifene) were announced by the National Cancer Institute (NCI), BCA's critical analysis and perspective were captured by major newspapers, including USA Today and the Chicago Tribune. The STAR trial studied the use of these two drugs in women who have not had breast cancer but who have a higher than average risk of getting the disease. While the results of the trial and many news reports talked about using the drugs in this setting as breast cancer "prevention," we noted that the results were about risk reduction, not prevention. In our press release, e-alert, and newsletter, we urged caution in interpreting the trial results, pointing out that while the NCI claimed that raloxifene was shown to be a better drug for preventing breast cancer, very few differences were actually found between tamoxifen and raloxifene.

**Think Before You Pink** BCA's campaign for more transparency and responsibility in breast cancer cause-marketing reached new heights. The campaign was featured in a segment of ABC's World News Tonight and in an extended piece on ABC's online show World News Now. Additionally, some of the key questions from the campaign were incorporated into cause-marketing efforts by other breast cancer organizations.

Answers Wanted BCA launched a new public education campaign, continuing to move beyond the standard breast cancer "awareness" messages that dominate Breast Cancer Awareness Month in October. Called "Answers Wanted," the new campaign focuses on fundamental questions in breast cancer that remain unanswered despite more than 20 years of breast cancer awareness and billions of dollars spent in research. The goal is to ask the hard questions that will lead to better treatment and true prevention of the disease.

While we achieved these outcomes, BCA also continued its truth telling advocacy on a wide range of issues in 2006.

# Telling the Truth to the FDA

BCA keeps close tabs on the actions of the United States Food and Drug Administration (FDA). We regularly submit testimony, report to our membership, and speak to the media regarding the agency's actions and activities.

BCA opposed the nomination of former NCI director Andrew von Eschenbach to the position of FDA commissioner due to conflicts of interest and a public statement in which he said that as commissioner he would speed the drug approval process, when the FDA's mission is to ensure the safety and efficacy of drugs. To voice our opposition, we sent letters to members of the U.S. Senate Committee on Health, Education, Labor, and Pensions and a letter to the editor of the *New York Times* in response to an article it published. Even though von Eschenbach was appointed, BCA's work on the dangers of rapid drug approval has helped lead to increasing public attention on the need to strengthen the FDA's regulatory functions.

Continuing our years-long opposition to the reintroduction of silicone breast implants to the open market, we urged the FDA to pay attention to new safety concerns about the devices. We also supported the call for an FDA investigation into the withholding of data by implant manufacturer Mentor Corporation and the treatment of the FDA whistleblower who revealed the information.

# Drug Pricing and Pills for Prevention

The issue of drug pricing reached the national stage in 2006. When the public and the media began to talk more about the cost of new biotech drugs—such as Herceptin and Avastin—BCA was able to take a strong position to tell people the truth about this issue because we don't take money from the pharmaceutical industry. We were able to publicly question companies like Genentech about their practice of pricing treatments beyond the reach of most patients. We also helped women with breast cancer tell their stories, including the challenges they faced due to the high cost of drugs, by connecting them to reporters and publishing their experiences in the BCA Source.

Following the release of the STAR trial results, BCA updated its organizational policy on pills for the so-called prevention of breast cancer. The policy explains the history of the use of pills to "prevent" breast cancer, and that we oppose a pills-based approach to breast cancer prevention because of the concern that pills will cause other diseases.



BCA's community organizer, Pauli Ojea, at the 2006 SF Pride event

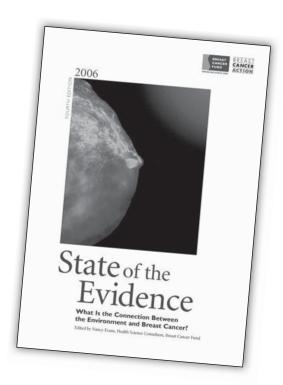
# Inspiring Environmental Change: Stopping Cancer Where It Starts

BCA has long believed that in order to prevent breast cancer, we need to know what in the environment is causing the disease. The only true prevention of breast cancer is to stop it before it starts—and a big part of that includes advancing public policies aimed at reducing and eliminating toxins to which we are exposed every day. While we advocate for research on the environmental links to breast cancer, we also urge a "better safe than sorry" approach to public policy. BCA's activities in this area include publishing analyses of research, policy advocacy at all levels of government, and public education.

In early 2006, BCA copublished the fourth edition of State of the Evidence: What Is the Connection Between the Environment and Breast Cancer? with the Breast Cancer Fund (online at www.bcaction.org/soe). The report reviews and analyzes nearly 350 scientific studies on environmental links to breast cancer. It also includes a ten-point plan to reduce the risk of breast cancer and ultimately end the epidemic.

As a core member of the Bay Area Working Group (BAWG) on the Precautionary Principle, BCA encouraged individuals and organizations to advocate within their communities for adoption and implementation of the precautionary principle of public health as a matter of public policy. The BAWG continued to work with government officials in Berkeley and San Francisco to ensure the successful implementation of their environmentally preferable purchasing ordinances.

Through our participation in the Environmental Health Legislative Working Group, BCA staff and volunteers participated in the coalition's Environmental Health Legislation Advocacy Days in Sacramento. BCA, along with our allies, educated California legislators about pending environmental health legislation.



# Telling the Truth About Cause Marketing: Think Before You Pink

BCA's efforts to encourage consumers to ask hard questions about pink ribbon products and promotions continued in the fifth year of the Think Before You Pink campaign. This web-based campaign (www.thinkbeforeyoupink.org) is BCA's counter to the messages about "Breast Cancer Awareness Month" in October, which suggest that activism should take the form of shopping for the numerous pink products available.

Think Before You Pink reminds consumers that they deserve to know how—if at all—their pink ribbon purchases and participation in pink ribbon promotions will support ending the breast cancer epidemic. The popular campaign also urges companies with pink ribbon marketing campaigns to be more transparent and accountable to people who buy their products.

The 2006 campaign featured an updated "Parade of Pink," a list of some of the hundreds of pink ribbon products and promotions on the market. The list highlights the overwhelming number of pink products that are marketed by big-name companies. The list of critical questions was also expanded to include how much money is being spent on marketing, and what the company is doing to assure that its products are not contributing to the breast cancer epidemic.

Response to the campaign has grown each year, with visits to thinkbeforeyoupink.org totaling more than 25,000 by the end of October. Additionally, the campaign was featured in a book, *Pink Ribbons, Inc: Breast Cancer and the Politics of Philanthropy.* 



How much money from each product sold actually goes toward breast cancer?

What is the company doing to assure that its products are not contributing to the breast cancer epidemic?

How much money was spent marketing the product?

# **Answers Wanted**

In its first year, this multiyear campaign addressed the need to know which breast cancers will metastasize and become life-threatening and which will not. It included a national poll of the public's awareness of this issue, an online quiz on breast cancer facts, and a direct-action opportunity telling congressional subcommittees on health to prioritize research that will give doctors the tools they need to determine upon diagnosis whether breast cancer will spread.

Our poll of 1,000 women and men across the United States found that most people are still confused about some of the most basic facts about breast cancer. But it also found that most people do know that their doctors aren't able to definitively answer a woman's most basic questions at the time of a breast cancer diagnosis: "Will I die from this?" and "What should I do next?" Answers Wanted is a public education campaign that asks the hard questions about breast cancer.



BCA's executive director, Barbara Brenner, speaking at the BCA Writers' Voices event

# Inspiring Change in Access to Care: Working for Universal Health Care

One of the most pressing health issues today is the need for universal access to health care. BCA strongly believes that every woman with breast cancer must be able to get the treatments she needs, and we are working to ensure this. For several years BCA has supported California state senator Sheila Kuehl's leadership in advancing universal health care legislation. In 2006 success was achieved as Kuehl's bill passed through both houses of the legislature. Though Governor Schwarzenegger vetoed the bill, BCA remains committed to working on this issue.

BCA partnered with other organizations and coalitions working toward universal access to care for all California residents. We helped organize four local health care forums in key communities throughout the state to empower and train women to take legislative action by sharing their experiences with policy makers. BCA also joined the executive committee of the Women's Working Group on Universal Health Care, a coalition of women's health organizations working on this issue. BCA brought the voices and experiences of people affected by breast cancer to the coalition with compelling stories of the catastrophic cost of a cancer diagnosis and treatment.

# True Information Is Essential

Women need to have access to all the information necessary to make decisions on breast cancer treatment, diagnosis, and screening. BCA has always been committed to providing accurate, reliable, and honest information about breast cancer. By doing so, BCA both enables people to make informed decisions and supports their activism. We provide information to anyone who needs it via our highly acclaimed newsletters, web sites, a monthly e-alert, and a toll-free number.

In 2006, we redesigned BCA's newsletter and gave it a name, BCA Source, to reflect how much it has grown over the years to become a trusted source of substantive information. We mailed it to an ever-expanding list of more than 17,000 individuals and institutions around the world. We published analyses of scientific and medical news, coverage of controversial subjects, book reviews, and profiles of activists. Published five times a year, we provided it free to anyone who requested it. The BCA Source continues to sift through the stacks of misinformation about breast cancer to give people the true story about the disease, and it remains highly regarded in the world of women's health.

BCA's Spanish-language newsletter, *Saber Es Poder* (Knowledge Is Power), focuses on issues of concern to Spanish-speaking communities. We distributed 1,600 copies of each issue to 250 organizations and individuals in 2006.

We also function as a resource for thousands of people through our acclaimed web sites and toll-free telephone number (877/2-STOP-BC). In 2006, via phone and e-mail, we provided direct support to more than 1,000 newly diagnosed women, people with questions about treatment options, new drugs or studies, people who were desperate for financial or legal resources, and friends and family members who were seeking information for their loved ones living with breast cancer. BCA's web site (www.bcaction.org), which received an average of 35,000 visits per month in 2006, serves as a comprehensive source of information for individuals around the globe. Our monthly e-alerts are distributed to more than 7,750 people around the United States, containing the latest information about breast cancer in the news, ways to take action, important upcoming conferences, talks and events about breast cancer, and answers to frequently asked questions.

BCA exists because far too many people have been affected by this disease. The work we do is made possible by the efforts of activists and everyday people who care deeply about breast cancer and those it affects. With the help and activism of so many people, BCA is able to continue telling the truth, free from corporate conflicts of interest, working toward an end to the breast cancer epidemic.



### **Donations**

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Jewelle Gomez, Peggy Orenstein, Sylvia Brownrigg, Michael Pollan, and Anne Lamott volunteered to speak at "Writers' Voices, an Evening for Breast Cancer Action."

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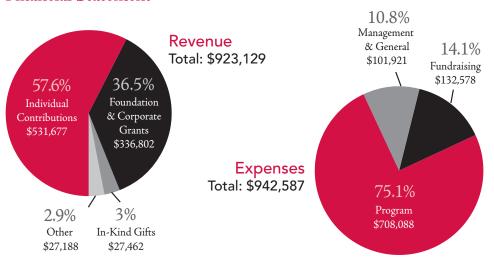
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