



BCA's Plans for the Future

By Barbara Brenner, Executive Director

More than a year ago, BCA began an intensive planning process to develop a five-year strategic plan that would best serve the needs of women with breast cancer, the needs of our members, and the needs of the breast cancer movement. Our process involved asking questions of our members, others in the breast cancer world, and ourselves. With this special issue of the *Source*, we are pleased to present the results of our planning process and the elements of our plan.

One thing we at BCA have always known is that we view breast cancer differently than the mainstream breast cancer movement. While much of the movement believes we can frame the idea of “The Cure” in medical or scientific terms, BCA does not believe the disease or the epidemic can be cured until the underlying causes of the disease are addressed. We are convinced that we need to reframe the conversation around “The Cure” to include more than exclusively medical or scientific ideas.

On the basis of this conviction, BCA is challenging assumptions about breast cancer and inspiring changes in how we approach the disease. And we have experience in how to do this. Nearly two decades ago, no one talked about environmental causes of breast cancer. We drove that conversation to the mainstream. More recently, we began the conversation about breast cancer cause marketing with our Think Before You Pink campaign, and as a result many more people are asking questions about the “pinking” of this dreaded disease. We now need to propel more changes in the conversation, focusing on the work that remains to be done in the field of treatment, the environment and breast cancer, and inequities in breast cancer outcomes.

The focus of BCA's work going forward will be in three priority areas. Each is discussed in more detail in the pages that follow. They are:

- ⊗ **Advocating for more effective and less toxic breast cancer treatments by shifting the balance of power in the Food and Drug Administration's drug approval process away from the pharmaceutical industry and toward the public interest.** As a result of this work, we will make sure that women and men with breast cancer have meaningful access to the best available treatments. Our independence from pharmaceutical funding and the work we have done to establish our credibility at the FDA make it possible for us to do this work.
- ⊗ **Decreasing involuntary environmental exposures that put people at risk for breast cancer.** As we have in the past, BCA will continue to advocate for corporate accountability and will engage the corporate community and government agencies to assure that manufacturing sectors are regulated by policies that prohibit these exposures. We have always believed that the concerns of marginalized communities are critically important to addressing environmental issues. We will therefore continue to build bridges between these communities and those who have the power to affect change.
- ⊗ **Creating awareness that it is not just genetic differences, but social injustices—political, economic, and racial inequities—that lead to disparities in breast cancer outcomes.** This understanding must be achieved if we are to be able to work at ending these injustices. While this understanding is beginning to pervade many health fields, the focus on differences in cancer incidence and mortality continues to be dominated by genetic and biological factors. BCA will reframe the breast cancer discussion to focus on inequities, whenever and wherever possible.

As the established watchdog of the breast cancer movement, BCA brings experience and passion in promoting the tough conversations and asking the tough questions. Our priorities are in line with our values of truth-telling and advocacy. They reflect the fact that BCA's work touches many constituencies while maintaining an independence that is unique in the breast cancer world. And, most importantly, they give people a variety of levels in which to engage in addressing breast cancer issues and ways in which we can engage them—from the personal to the political.

In the words of our founder Elenore Pred, breast cancer is not just “an individual woman's tragedy—it is a tragedy for all women. It is a political and economic tragedy played upon our community, national, and world stages.” Elenore's spirit continues to guide us today, and it is in her spirit that BCA now moves forward into the next phase of our work.

The changes that have happened to date in the breast cancer world took place because people just like you demanded them. Nothing BCA accomplishes is possible without the commitment and energy of many, many people. We trust you will find in our plan something that speaks to your concerns in the breast cancer field, and we look forward to working with you to achieve our ambitious goals. ⊗

STRATEGIC PRIORITY

Advocate for more effective and less toxic breast cancer treatments by shifting the balance of power in the Food and Drug Administration's drug approval process away from the pharmaceutical industry and toward the public interest.

By Lisa Wanzor, Associate Director

Since Breast Cancer Action's first days, the organization has been on the forefront of applying a critical analysis to current and emerging treatments and medical devices used in breast cancer. BCA's founders honed their skills on the science of breast cancer, sharpened their critical analysis of clinical trial data, and raised advocates' voices at federal government agencies where cancer policy was being made. These efforts drove the mission of BCA then as it does now.

BCA has always put the needs of women with breast cancer first, and we will continue to work to assure that the FDA does the same.

One of BCA's new strategic priorities is a fine-tuning of our founders' vision. Only one of our founders is alive today, but we are pleased to honor the vision they set forth nearly two decades ago. Continuing our watchdog role, BCA will advocate for more effective and less toxic breast cancer treatments by shifting the balance of power at the FDA away from the pharmaceutical industry and toward the public interest. The FDA must act with integrity and without conflicts of interest to be the strong and effective

agency that patients need it to be. BCA's independence from pharmaceutical company funding puts us in a unique position in the breast cancer movement to advance this ambitious goal. BCA has always put the needs of women with breast cancer first, and we will continue to work to assure that the FDA does the same. And there is clearly work to be done.

In early 2008, the FDA allowed fast-track approval of Avastin as a breast cancer treatment. At that time, the drug was already approved as a lung cancer treatment and was being prescribed off-label for breast cancer patients. Even though the FDA found that no survival data were available and that

data showing improvement in quality of life were not sufficient, Avastin was granted fast-track approval by the FDA. Fast-track approval means that its manufacturer, Genentech, will need to provide additional supporting data in the future. Studies have indicated that Avastin might be helpful for women with metastatic breast cancer, but the data do not show this yet. BCA believes that drugs should be approved only if they improve overall survival or quality of life, or if they cost less and are as effective and safe as current treatments. The current data available for Avastin do not show this, but with fast-track approval of the drug, Genentech's stock price soared.

Erythropoiesis-stimulating agents (ESAs), on the other hand, had long been approved for anemia in cancer patients undergoing chemotherapy. New data in 2007 indicated dangerous side effects for some cancer patients. The data also produced some debate about whether the drugs were harming or helping cancer patients. BCA applauded the very complicated ruling issued by the FDA restricting the marketing of ESAs for certain cancers, including breast cancer. ESA manufacturer Amgen's stock prices plummeted.

Hormone therapy (HT) had long been questioned by BCA as increasing breast cancer risk, though prescribed by many doctors for women entering menopause. Finally in 2002, the news hit the headlines that HT was increasing the risk of breast cancer. Wyeth, the HT manufacturer, was forced by the FDA to add a warning label, and HT sales stopped in their tracks. Some researchers have attributed the recent dip in breast cancer incidence rates to the reduction of HT taken by older women since these data were released.

Clearly, the FDA's decisions have major implications for drug companies and for patients as well. With this in mind, BCA and many others have grave concerns about the independent functioning of the FDA when it is heavily funded by the companies that it regulates. For these reasons, much work

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STRATEGIC PRIORITY

Decreasing involuntary environmental exposures that put people at risk for breast cancer.

By Pauli Ojea, Community Organizer

BCA has been committed to reducing environmental exposures to toxins linked with breast cancer since the organization's inception 18 years ago. At that time, very little attention was given to the connection between the environment and breast cancer. Through the years, as a result of BCA's efforts as well as those of our allies, the environment's relationship to breast cancer and other diseases has received more attention, both in the research lab and among the general public. Although more research and public awareness about environmental links to breast cancer are needed, we have seen some success thus far.



Success has not followed as quickly in the responses of corporations and government to the growing scientific evidence regarding environmental exposures. Gaping holes remain in public policies that still allow corporations to use and manufacture suspect chemicals that put people in harm's way. We continue to see cancer-causing substances in our everyday products, pollution in our neighborhoods, and unsafe exposures in our workplaces. We also see injustice, with certain people (namely low-income communities and communities of color) bearing a greater burden of harm than others.

BCA seeks to change that picture by focusing on involuntary environmental exposures as one of our strategic priorities. Part of this work involves urging corporations to change their practices. We will focus our attention on companies that associate themselves with breast cancer (by putting a pink ribbon on their product to raise money) but whose products contain ingredients linked to the disease. BCA calls these companies "pinkwashers." Our Think Before You Pink campaign has urged numerous pinkwashers to clean up their act, including calling on cosmetics and car companies to make cleaner products in order to really make a difference in breast cancer. We believe that if a company purports to care about breast cancer, it should be doing as much as possible to ensure that its products are not contributing to the epidemic.

We also understand that when one company makes a change for the better, a ripple effect occurs in the market, with more companies following suit, resulting in more healthy choices for consumers. Our Think Before You Pink campaign will continue to push pinkwashers to make the kinds of changes that will truly make a difference in breast cancer—stopping the disease where it starts.

As BCA works to change corporate practices, we will also encourage our governments to enact the necessary policies that will help keep toxic chemicals out of the environment and out of our bodies. BCA is currently involved in the

growing movement for chemical policy reform in California and beyond. We want to see public policies that will more adequately regulate harmful or untested chemicals. Broad policy changes such as these will mean that all individuals will be less exposed to toxins. So, whether you are a worker who is exposed to a questionable chemical or a consumer who buys a household product that contains it, this kind of change in chemical policy will help protect you.

As with so much of BCA's work, our attention on the issue of environmental health and justice will focus on the systemic changes necessary to keep people safe. While there are some opportunities for people to make healthier choices for themselves, our work will focus on the exposures that people can't control on their own. For example, an individual can make the choice to exercise outdoors for good health, but policy decisions affect whether the air that person breathes is healthful. BCA will advocate for policies that will ensure that the air (and water, land, and food) is clean and good for our health.

Our vision is a world in which no consumer has to wonder whether the product she or he is buying contains dangerous chemicals, no mother has to fear that her children's toys are toxic, and no worker is getting sick because of her or his job. It's

“ While there are some opportunities for people to make healthier choices for themselves, our work will focus on the exposures that people can't control on their own. ”

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STRATEGIC PRIORITY

Creating awareness that it is not just genes but social injustices—political, economic, and racial inequities—that lead to disparities in breast cancer outcomes.

By Brenda Salgado, Program Manager

For numerous illnesses, serious health inequities exist between different racial and economic groups, and breast cancer is no exception. African American women with breast cancer die at a higher rate than any other racial group, and studies reveal that African American and Latina women diagnosed with breast cancer are less likely to receive standard of care treatment. Low-income women are less likely to have employer-sponsored health care, placing them at great financial risk if they are diagnosed with breast cancer.

Of course, these inequities occur in the larger context of our social and political environments. For example, people who live close to a hazardous waste site are at increased risk for

breast cancer, even after adjusting for known risk factors. They are also more likely to die of breast cancer. Historically, toxic sites have been situated predominately in communities of color and low income communities, which then bear a disproportionate burden of exposure to harmful chemicals.

In the social justice and public health fields, discussions about eliminating health disparities have already begun to focus on addressing the root causes in our social and physical environments. Low-income children of color have much higher asthma rates. Alongside efforts to provide asthma education and medical care, many public health officials recognize that poorly built housing, diesel truck traffic, and poor air quality in and near schools are significant contributors to this health inequity.

In the breast cancer world, though, research on disparities has focused primarily on two areas: genetics and personal behavior. Studies have examined the prevalence of BRCA gene mutations and differences in screening rates, obesity, and diet of breast cancer patients of different races. While these point to pieces of the puzzle, they tend to focus on an individual woman's inheritance of "faulty" genes or her responsibility for having "caused" her disease.

BCA challenges this conventional approach to addressing breast cancer disparities. Eliminating differences in breast cancer incidence and outcomes requires us to look deeply and honestly at how issues of race, economic status, and political power—things outside an individual's control—affect who enjoys good health and who does not, and whether or not

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Health inequities are "differences in health that are unnecessary, avoidable, unfair and unjust" and they are related to "discriminatory actions, practices and policies that perpetuate diminished opportunity and hazardous exposures for certain populations."

ALAMEDA COUNTY PUBLIC HEALTH DEPARTMENT



Treatments...

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remains to be done as we strive for more effective and less toxic treatments for breast cancer patients. BCA will remain a respected voice offering a crucial public health and patient perspective to counter the hype of pharmaceutical press releases and attention-grabbing news headlines. BCA will continue to work toward a future when all patients have access to and receive the gold standard of breast cancer treatment no matter their income, insurance status, ethnicity, or any other factor. In the meantime, BCA renews its efforts to free the FDA from pharmaceutical interests, enabling the FDA to fulfill one of its most important obligations—protecting patients.

BCA's plan is to educate its members about the FDA while identifying the opportunities where public pressure can compel change. In our role as a watchdog, BCA will continue to provide analysis and comment when drug and device applications are being reviewed. We will expose decisions, structures, and policies that seem more aligned with the interests of the pharmaceutical industry than the interests of patients and work to change them. We will also build alliances with organizations sharing these common goals. Increasing BCA's presence in Washington, D.C., we will be better poised to advocate for public health-centered policies. With allies and a growing membership our voice will be stronger. The future of breast cancer treatment is in your hands. Together, we can affect positive change at the FDA. Please join us. ☘

19,000 POSSIBILITIES

Help Make BCA's Strategic Plan a Reality

By Amy Harris, Development Director

These are very exciting times for Breast Cancer Action. Now that our three strategic priorities are clearly defined, the real work of implementation begins. With this comes the realization that we need many resources to accomplish our goals.

We have said many times that we make no small plans at BCA. This couldn't be more true as it relates to the people power and array of resources that are necessary to execute our strategic plan. The great news is that Breast Cancer Action is first and foremost a grassroots membership organization with an active nationwide membership of over 19,000 strong. As we know from our history of success, anything is possible.

We need your help to move forward in achieving our plan. Together, we will carry the voices of people affected by breast cancer to inspire and compel the changes necessary to end the epidemic. Following is a list of opportunities—from activism to professional services—to help BCA begin moving forward. We hope the list will spark you to thinking about the ways in which you can help BCA to challenge assumptions about breast cancer and inspire changes in how we look at and approach it.

Please accept our call to action and contact us today at 877-2STOPBC or info@bcaction.org to let us know how you can help make our vision of the future a reality.

Activism and People Power

- ✳ Sign up for BCA's monthly E-alert.
- ✳ Forward the E-alert to your friends and family.
- ✳ Write letters to the FDA demanding drug approval standards that put patients' interests ahead of pharmaceutical company concerns.
- ✳ Write letters to "pinkwashers" asking them to make their products cleaner.
- ✳ Sponsor BCA at a conference on cancer "disparities."
- ✳ Blog about BCA.
- ✳ Add BCA to your Facebook and MySpace friends list and link to us from your profile.
- ✳ Write a letter to the editor of your local newspaper.

Individual Donations

- ✳ Help make our strategic plan a reality with a donation of \$5,000 or more.
- ✳ Make a donation that is personally significant to you.
- ✳ Join the Susan Stone Circle by committing to make monthly donations to support BCA's work.
- ✳ Include BCA in your estate plans and join the Elenor Pred Circle.
- ✳ Join the Susan Claymon Advocacy Fund with a gift of \$250 and send BCA advocates wherever they are most needed.
- ✳ Ask your employer to match your donation.

In-Kind Donations

- ✳ Sponsor a BCA ad in your favorite publication.
- ✳ Host a house party.
- ✳ Donate your car.
- ✳ Donate office supplies.

Professional Services

- ✳ Graphic design of BCA print materials (invitations, note cards, signs, etc.)
- ✳ Provide catering or space for a BCA event.

Corporate Donations

- ✳ Sponsor a BCA event.
- ✳ Contribute a portion of sales from your business to BCA. (Please review our corporate contributions policy to assure that your company is consistent with it.)

And know that, to BCA and the many thousands of people we represent, all of your support makes a world of difference. ✳

“ Together, we will carry the voices of people affected by breast cancer to inspire and compel the changes necessary to end the epidemic. ”

DONATIONS

Looking for the "Donations in Honor" and "Donations in Memory" section? Don't worry, we didn't forget it. Due to this month's special online issue, we've saved the listings for the next print issue of the *Source*. It will contain all donations made to BCA in honor and in memory of your loved ones from March to July 2008. Thank you for your continued support.

Environmental exposures...

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a world in which all people are equally protected from exposure to harmful substances, thus leading to fewer cancer cases down the road.

Attaining such a world will not be possible without the collective action of many people. At BCA, we will work to ensure that you, our members, are fully informed about opportunities to use your voice to create a safer world. ✖

Social injustices...

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communities are engaged in the decision-making processes that will ultimately affect their resources and overall health.

We must push researchers and the broader breast cancer movement to take this larger view with us. We have much work to do to achieve this.

For example, a study in May 2008 focused on teenage girls, showing that regular physical activity may reduce their risk for breast cancer later in life. A resulting news article admonished readers to “get your daughters off the couch.” Similarly, studies have shown an increased risk for breast cancer in postmenopausal women who are overweight.

What is missing in these reports is the larger context: the choices we make are shaped by the choices that are available to us. A healthy diet and regular exercise are important for all of us, but they are about more than self-discipline.

Some neighborhoods have easy access to healthy and organic foods; others have only fast food restaurants and liquor stores nearby. Some communities have safe streets and green environments in which to run and play, while others are unsafe to walk even during the daytime. Some have safe housing with minimal exposure to environmental contaminants, while others are near toxic release sites or live in communities built with cancer-causing materials.

Like the hazardous waste facilities, these neighborhood differences follow a pattern. They reflect communities with differences in race and income.

If we truly seek to reduce inequities in breast cancer, we must act to address their root causes. As we advocate for all breast cancer patients to receive the best care available, we must simultaneously urge solutions for the injustices that keep so many communities unhealthy in the first place. As a society we must recognize that improving social and economic conditions is a decision to afford everyone equal access to prosperity and good health.

As BCA continues to take these conversations from the personal to the political, we will push for researchers and the cancer community to widen their lens and understand that a world divided by social inequities poses great ethical challenges for improving health, and that a strict focus on genetics and personal behavior is simply not enough.

BCA has changed many conversations in breast cancer, and we will work to change this one as well so that people will see breast cancer through a social justice lens in order to eliminate the inequities in breast cancer. We must work to create policies that will ultimately make healthier lives an option for all of us.

In the words of Elenore Pred, “Together, we have the power to change things.” Please join us on this journey to change the conversation about differences in breast cancer incidence and mortality. ✖

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