



Summer 2010

Issue 110

BCA Turns 20! You're Invited!



October 7, 2010
 The City Club, San Francisco, CA
 6 pm Sponsor Reception
[7 pm Main Celebration](#)

We'll be honoring Barbara Ehrenreich, Rachel Morello-Frosch, Belle Shayer, and all of those who got us to where we are today! Tickets will be available online starting July 19th. Until then, please contact Development Director Amy Harris for [ticket level and benefits information](#) at aharris@bcaction.org or 415-243-9301 x15.

20 years later: Belle Shayer

By Belle Shayer



Editor's note:

Belle Shayer is the only surviving founding leader of Breast Cancer Action. After she was initially treated for breast cancer in 1984, she was told she was cured. When her cancer recurred in 1988, she felt shattered, frightened, and furious. But she did her homework, studied her pathology report, and told her doctor she wanted a second lumpectomy rather than the mastectomy he'd recommended. He balked, so she found another doctor

who didn't. Belle Shayer turned from breast cancer patient to breast cancer advocate as a result. She is 80 years old, lives in the San Francisco Bay Area, and still advocates on behalf of Breast Cancer Action.

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I was recently asked to reflect on breast cancer advocacy over the last 20 years. My first thought was that, back in 1990, I never dreamed BCA would still be needed in 2010. When we started out, what made us do it was the fact that nobody else was doing it. Our goal was to let everyone know about breast cancer, to shout about it from the street corners. Even if you didn't have it, you were going to be touched by it — your mother, your daughter, my daughter, your sister, a friend — someone you knew was bound to have breast cancer, and at some point, you would be touched by it.

Twenty years ago, having breast cancer was a family secret. No one knew what the stages of cancer meant: stage 2, 3, 4? When we had to make the horrible decisions — mastectomy, lumpectomy, chemotherapy, radiation — we didn't know where to go for information to make the right decisions. When I was faced with the prospect of a mastectomy, I had no idea what I would look like after the surgery. I kept asking, what does a woman look like missing a breast? I kept asking, but no one would answer me. Nobody wanted to talk about it. I kept pushing and finally found a plastic surgeon who would show me pictures. While they were horrible, at least I knew how I would look!

What's changed for women with breast cancer over those 20 years? Much has changed. Much has not changed.

What has not changed is that same fear, panic, and confusion upon getting a diagnosis of breast cancer. There is the same fear and frustration that, no matter what you do, you may have a recurrence, and it is totally beyond your control. There is still the need for support groups, advocacy, and education. President Richard Nixon declared war on breast cancer, and more than 40 years later, we're still fighting that war, yet there's more funding for research than ever before. How is research money being spent? What's currently being researched? Whose research is being funded? How are funding decisions made? Why isn't this process more transparent?

And then other questions come to mind that need to be addressed. We need to question why corporations do not examine if and/or how they pollute the environment and whether they may be contributing to breast cancer. The statistics (which I cannot cite right now, but you probably can) are still high for those women who are diagnosed because of environmental toxins. Low-income women still do not get adequate health care, and funds are not available for them to pay for child care, housekeeping, healthy foods, resting and recovery time, prescription costs, and treatment options.

What has changed is that there is more information and quicker access to it, thus greater awareness. People are no longer afraid to speak out; they willingly

come forward to support those diagnosed. "Lay" people are now consulted, sought out, and invited to participate with state and federal agencies and research groups. Some breast cancer organizations are more willing to work together and with environmental organizations for the common good.

It was very hard at the beginning, because we were women living with breast cancer. We were the doers, going to Congress, writing the letters, doing the newsletter, and lobbying for recognition, all while undergoing radiation and chemo. Many of us had kids, husbands, and families, and we were basically the workhorses behind it all. It was very hard to keep the energy going. There was very little money, no such thing as grants at that time, and we usually paid for everything ourselves, the postage, the printing, that kind of thing. It's hard to do all this while you're meeting with your doctors, being a wife and mother, reassuring everyone. It's very draining.

Unfortunately, breast cancer has now become a flourishing industry for drug companies, hospitals and physicians, corporations, and retail businesses, which makes me wonder: is there really is a commitment to ending breast cancer?

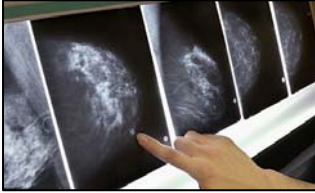
Much has changed. Much has not changed. Much remains to be done.

I would like to express my tremendous admiration for everyone who is and has been part of BCA. Each one has contributed so much and worked so hard. I am so very grateful and proud.

Yours,
Belle Shayer

BCA Releases Updated Screening Policy

By BCA Screening Task Force: Lauri Andress, Vernal Branch, Barbara Brenner, Zoe Christopher, Alicia Harris, Ellen Leopold, Tracy Weitz, Barbara Wiener, and Jane Zones



The confusion that emerged in response to the new USPSTF screening recommendations prompted us to convene a BCA Screening Revisions Taskforce. After five months of review and research, we have released our Screening Recommendations and Policy to clarify the benefits of breast cancer screening, and to offer recommendations for women of all ages on how to make fully informed decisions about screening. To obtain a copy of the policy, you can go to: <http://bcaction.org/uploads/PDF/BCA%20Screening%20Policy%20-%20Final%202010.pdf>.

From the Executive Director:

Getting the Right Test Can Determine the Right Treatment and So Can What the FDA Does.



By Barbara Brenner

You may have noticed a recent *New York Times* article "A Study Offers Clues on Therapy for Cancer" (4/28/10) about the challenge of accurate testing to determine what drugs are appropriate for cancer patients, particularly breast cancer patients. As we've come to expect, the press was covering an issue we've been concerned about for some time.

Most of the widely touted progress in "personalized cancer care" has been made in breast cancer. The two most common "personalized" approaches have to do with testing for a tumor's sensitivity to estrogen or progesterone (indicating the appropriateness of hormonal treatments like tamoxifen or an aromatase inhibitor), or testing for the overexpression of the Her2/neu protein (indicating the appropriateness of treating with Herceptin).

So far so good. But it turns out that the tests for these two things are not so easy to do, and quality control over the accuracy of the tests has been minimal. As a result, some patients who might benefit from hormonal or Herceptin treatment are scored as "negative" and never get the treatment. Others, who

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actually won't benefit from the treatment, are incorrectly scored as "positive" and get treatment that won't help them — and may have dangerous "side" effects. Still other patients, whose tests results are ambiguous, are cast into a sea of uncertainty.

The problem of these tests' accuracy has been discussed by breast cancer activists for years. Finally, the American Society of Clinical Oncology (ASCO) and the College of American Pathologists have issued guideline recommendations for testing of both hormone receptors and Her2/neu. (The documents are very long and technical, but we'd be happy to send you copies of these guidelines if you're interested in seeing them.)

The next step, of course, is to make sure that practicing oncologists and pathologists know about and follow the guidelines. Lots of guidelines have been issued that are never followed. And educating doctors in community practice is the hardest part of making guidelines real. Maybe ASCO and the College of American Pathologists will devote some resources to educating doctors beyond their already well-informed circle. We can hope.

Since the treatments for people whose cancers are either hormone positive or Her2 positive work for only some, we need more research to determine who will in fact benefit. We also need research into treatments that will work for those with the markers, but who don't benefit from the drugs currently available.

Some of that work is happening — Genentech, the maker of Herceptin, is doing some of it. But in a dangerous twist, the company is urging the FDA to let it market drugs that have not been fully tested for efficacy and safety. They have approached the FDA for approval of a drug called TDM-1 (for patients whose breast cancer overexpresses Her2/neu, but for whom Herceptin has stopped working) on the basis of a single test of the drug in a study that did not involve a control arm of women getting standard treatment.

Since BCA is committed to making sure that drugs approved for the breast cancer market either prolong life, improve quality of life, or cost less than drugs currently on the market, [we have asked the FDA to reject Genentech's request for approval of TDM-1 at this time.](#)

The positions we take are not always popular. But we're not trying to win a popularity contest. We're trying to make sure that decisions about the care patients receive are being made by people who have those patients' interests foremost in their minds.

For additional notes and BCA thoughts on breast cancer developments, as discussed at the 2010 American Society of Clinical Oncologists (ASCO) meeting, visit: <http://bcaction.org/index.php?page=american-society-of-clinical-oncology>.

Giving Teeth to the Toxic Substances Control Act

By Kimberly Irish, BCA Program Manager

For the past 20 years, Breast Cancer Action has repeatedly called on elected officials to protect our environment, work toward eliminating social inequities related to breast cancer incidence and outcomes, and put patients before company profits. Our long-term strategy includes advocating for comprehensive chemical reform, which includes addressing the holes left in the outdated Toxic Substances Control Act of 1976 (TSCA).

To advance this goal, BCA recently signed on in support of the Safe Chemicals Act of 2010, which will modernize key elements of TSCA. This legislation requires the safety testing of all industrial chemicals and shifts the burden to the chemical industry to prove that chemicals are safe in order to stay on the market. TSCA was last reformed 34 years ago, so an overhaul is long overdue.

Some of the key changes proposed in the Safe Chemicals Act include:

- Providing the Environmental Protection Agency with enough information to judge a chemical's safety, prioritizing chemicals on the basis of risk
- Ensuring that all chemicals on the market meet a certain safety threshold
- Addressing the highest risk chemicals quickly
- Creating open access to reliable information on chemicals
- Promoting green chemistry

Sen. Frank Lautenberg (D-NJ), Rep. Bobby Rush (D-IL), and Rep. Henry Waxman (D-CA) introduced the legislation in April in order to better protect Americans from toxic chemicals in everyday household products. Current law does not require manufacturers to prove that their products are safe before selling them; in fact, only about 200 of the over 80,000 chemicals on the market have actually been tested for safety. Clearly, that's not enough. BCA is working toward a standard whereby chemical manufacturers, not consumers, bear the burden of proving their products are safe. We applaud Sen. Lautenberg and Representatives Rush and Waxman for their leadership on this important issue!

"What the Cluck?" Update

By Angela Wall, Communications Manager



In April 2010, Breast Cancer Action received a lot of angry comments via Twitter, Facebook, and e-mail from people outraged by the KFC/Komen "Buckets for the Cure" campaign. Motivated by your voices, we launched an online advocacy campaign called "What the Cluck?" Over 5,000 people took action and sent letters to the KFC and Komen leadership protesting the "Buckets for the Cure" campaign.

Your voices made an impact. This campaign was covered extensively by national media, including blogs of the *Wall Street Journal*, NPR, and Fox News, and by Comedy Central's [Colbert Report](#).

This is what carrying the voices means. It's about getting loud when we don't agree. It's about demanding accountability. It's about moving breast cancer away from corporate profiteering and towards women's health and better access to healthier food and lifestyle choices. Our voices carried a clear and important message: putting pink ribbons on buckets of chicken is not going to end breast cancer and may cause people to think that the chicken is harmless.

New Program staff Ramped Up and Ready to Go

Interview by Angela Wall, BCA Communications Manager

Breast Cancer Action welcomed two new staff members to the Program Office over the past few months. Alicia Harris joined BCA as a program associate, and Kim Irish joined as the program manager. Together, they augment our program-based work, perform outreach, maintain existing partnerships and build new ones, and keep our campaigns on track and moving forward.



[Alicia Harris, Program Associate](#)

I grew up in San Diego, California, with my parents and an older sister. Most of my family lives within four miles of my parents' house, so I shocked everyone by choosing New York to go to college! After graduating in 2008, I immediately moved to San Francisco to be a little closer to family.

My degree is in political science, but it's difficult for me to name just a few issues that I'm interested in. My primary "concern" is ensuring justice for all and ending oppression and domination wherever it exists. That's lofty, I know, but

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I'm an idealist. I don't believe "issues" occur in a bubble, so I'm interested in racial justice, economic justice, ending gender and sexual oppression, health access, and environmental justice — all deeply interconnected.

As the program associate, I build programs with Kim, sit on coalitions, and develop educational materials to advance BCA's priorities — particularly creating healthy environments and eliminating social injustices that determine how people are affected by the disease.

There's always more work to be done, and it can be overwhelming. I think all of us at BCA wish that there wasn't a need for our organization, but every day it's evident that there is.

When I first heard about BCA, I was impressed by the organization's approach to probing the systemic injustices in breast cancer incidence and outcomes. My job requires me to ask some important questions. Who suffers disproportionately from unhealthy environments? Who makes the decisions that perpetuate this? Why? In the U.S., where incidence is highest, millions of dollars are raised for breast cancer "awareness," but how is that money being used? When I speak to people about breast cancer, I'm always stunned at how little information people have about this disease. A lot of people think "pink ribbons" or "family history" when they think of breast cancer, and that's a problem — one that has a lot to do with who "holds the mouthpiece."

In addition to her work at BCA, Alicia is a member of CUAV (Community United Against Violence) and is also part of the Youth Leadership Council of [Bitch Magazine](#).

[Kim Irish, Program Manager](#)



I grew up in Sacramento, California, with my mom, dad, and younger sister. I came to San Francisco to attend law school. This city is one of my favorite places in the world, and I love the people who live here — the diversity, the incredible food, the beautiful scenery.

I describe myself as an activist, but I've thought of myself as one for only about seven years. Through law school and internships, I received an education in advocacy, working for Legal Services for Prisoners with Children, Equal Rights Advocates, Law Students for Reproductive Justice, and the USF International Human Rights Clinic.

I heard about BCA through friends in the Women's Policy Institute. In addition to breast cancer politics, I'm interested in women's health, women's rights and

empowerment, reproductive justice, and immigrant rights. All too often, breast cancer politics typically focus on the mainstream part of our society, while ignoring the margins. In more recent years, it seems there has been a shift toward more overlap and inclusiveness among organizations on the margins and some mainstream groups. This common ground creates discussions that get us further, especially, for example, when it comes to eliminating social inequities and barriers to accessing health care.

Breast cancer has affected many women in my family, including my maternal grandmother, my mother, and my mother-in-law. I have a very personal connection with breast cancer. And since arriving at BCA, I think more broadly about what it means to talk about the “causes” of breast cancer than I did before I started working here. I’m also more critical of corporations’ involvement in the cancer industry.

What does a program manager do? I make sure that BCA’s programming fulfills our organizational priorities of putting patients first, creating healthy environments, and eliminating social inequities. I work closely with the program associate, deputy director, and executive director to oversee BCA’s programs and program-based campaigns, including Think Before You Pink, Milking Cancer (our campaign to eradicate rBGH from the world dairy market), and California Healthy Nail Salon Collaborative. Additionally, I collaborate with BCA staff to reform state and federal chemical, environmental, and social justice policies, and to foster our grassroots activities and national presence.

In addition to working at BCA, Kim sits on the board of directors of Human Rights Advocates, a nongovernmental organization that does advocacy work at the United Nations, and of the Good Ol’ Girls, a social and networking organization for Bay Area progressive women.

DONATIONS IN HONOR

BCA gratefully acknowledges donations made in honor of the following individuals between March 3, 2010 and May 14, 2010.

Rita Arditti
from Anonymous

Tina H. Jones
from Stephanie Schus

Barbara Brenner
from William Ash
from Noreen Vera Purcell
from Anna Saenz

Bernice Karlsberg
from Linda and Mark Karlsberg

Barbara Brenner and Susie Lampert
from Joseph S. Brenner

Donna Keiran
from Jennifer Morgan

BCA Staff
from Amy L. Harris

Kendra Klein
from Nancy and Roger Klein

Jackie Beer
from Jacqueline Brooks

JoAnn Loulan
from Dee Mosbacher and
Nanette Gartrell

Breast Cancer Patients
from Evelee Harrison

Lynne and Brian
from Karen Kopelson

Metaxia Dalikas
from Aesthetics Plus, Inc.

Marla
from Linda Stein

Elena
from Linda Stein

Rachel Morello-Frosch
from Marta Morello-Frosch

Joan Frost
from Mally Arad

My Mom
from Anna Saenz

Aruna Gamblein
from Jacqueline Whittier Kubicka

Jeff Paris
from Jeanne Hunter

Roberta Gelb
from Anne-Marie Kunzler

Pearl
from Linda Stein

Lynda Gilgun
from Debra Fidler

Kelly Rapp
from Michelle and Roxy Rapp

Barbara Gowin
from Leslee and Dan Young

Sasha Rau
from Frances Gleitman and
Marilyn Trager

Mimi Heebe
from Lindsay Farino

Barbara Redding, My Mentor
from Diane Dodge

Jann James
from Ed James-Beckham

Dana J. Robinson
from Rebecca Farmer

DONATIONS IN HONOR continued
March 3, 2010-May 14, 2010

Pat Rowllins
from Leslee and Dan Young

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from Jerome Sobieraj

Loni Sinclair
from Jacqueline Whittier Kubicka

Marla Stein
from Garen Corbett

DeAnna Tibbs
from Jeanne Hunter

Vivian Trotz
from Lester Garfinkel

Those Living With Metastatic Breast Cancer
from Susan A. Brain

Kathy Gasper Welch
from Marsha Williamson

DONATIONS IN MEMORY

BCA gratefully acknowledges donations made in memory of the following individuals between March 3, 2010 and May 14, 2010.

Rita Arditti
from Edith Benveniste
from Julia Lichtig
from New Words Live Inc.

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from Nick Azer

Elaine Barnes
from Karl Kaikinger

Jeraline Brown
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Shirley Lutz
from Lanette Lutz

Marie Louise
from Barbara Belmont

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March 3, 2010-May 14, 2010

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from Mary-Ellen Maynard

Laura Moseley
from Pam Heaton

Mom
from Barbara Belmont

Virginia Moyer
from Nina Moyer

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from D. Abood

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Valerie Ann
from Bren Eckles

Marilyn Wagner, PhD
from Karen Kopelson

Jackie Winnow
from Helen Vozenilek

Micky Wolfe
from Virginia Wolfe

Alicia Osias Zabat
from Jennifer Nazareno

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- **Caren Cummins** for her steady & joyful office support.
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- **Linda Thai** for volunteering her time in the development department.
- **Brittany Shane** for choosing BCA as the beneficiary of her show at The Hard Rock Café.
- **Kathie Maxwell** for hosting a fundraiser for BCA.
- **Lisa Taylor**, our spring intern, for all her help and volunteer hours.
- **Sixth Annual Billie E. Loulan Memorial Luncheon benefitting BCA:**
 - **JoAnn Loulan** for hosting
 - **Donna Andrighetto** and **Lisa Troedson** for co-hosting
 - **Tracy Weitz** for speaking
 - **Amber Raimes** for donating her time and design expertise.
 - **David Fleishhacker** for volunteering his time as an auctioneer
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