



HONORING THE PAST, CREATING THE FUTURE



BREAST CANCER ACTION Annual Report 2000





BREAST CANCER ACTION

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A MESSAGE FROM THE BCA LEADERSHIP

In the ten years since Breast Cancer Action was founded, a mighty breast cancer movement has developed, and BCA remains at the forefront. From meetings in the homes of women living with the disease, Breast Cancer Action has grown to become a national organization that gives voice to thousands of people affected by breast cancer. The organization is one of a handful of women's health organizations that understands the complex role that politics and economics play in the development, detection, and treatment of breast cancer. Thanks to that understanding and the support of people around the country and throughout the world, BCA is able to empower individuals to take charge of their health and to confront the formidable forces that stand in the way of ending the breast cancer epidemic.

We are proud that, as the result of a decade's work, BCA is well positioned as a leader in the struggle to reach a future free of breast cancer and to put ourselves out of business. We are deeply grateful for the generous support of the individuals, foundations, and businesses that make it possible not only to honor our past, but to envision a future in which BCA no longer needs to exist. In the meantime, we are ready to be here for as long as it takes.


Jane Sprague Zomes
Board President


Barbara A. Brenner
Executive Director





BREAST CANCER ACTION MARKS A DECADE OF ACTIVISM

Ten years ago, a group of women in a San Francisco breast cancer support group—frustrated by the lack of information about their disease and by the complacency of scientists and government officials—decided to get organized. Led by Elenore Pred, a real estate agent and mother of two daughters, the women sought a way to bring attention and increased funding to breast cancer, which at the time was rarely even talked about in public.

Pred had been diagnosed with breast cancer in 1981, and after undergoing a mastectomy and chemotherapy, was told by her doctor that she was cured. But nearly seven years later, while working with the Peace Corps in Morocco, she found a lump on her collarbone that signaled a recurrence. A veteran of the civil rights and antiwar movements of the 1960s, Pred quickly set out to educate herself about not only the medical but also the political and social aspects of the disease, learning about the inner workings of federal health and research agencies while immersing herself in medical literature.

The first organizing meeting of what would soon be known as Breast Cancer Action took place in Pred's living room in July 1990. (Other names proposed—and summarily rejected—included Abolish Breast Cancer, or ABC, and Friends of Women with Breast Cancer.)

The founders took their cue on strategy from leaders of the AIDS advocacy movement, which had succeeded in bringing public attention to the scourge of their disease; stimulated billions of dollars for research, treatment, and education; and revolutionized the testing, release, and financing of AIDS drugs. The founding mission of the organization was to make breast cancer a national priority by serving as a catalyst for the prevention and cure of the disease.

Breast Cancer Action has evolved significantly over the past decade. In the broadest sense, the changes in the organization are reflected in the evolution of the mission statement, which now reads: *Breast Cancer Action carries the voices of people affected by breast cancer to inspire and compel the changes necessary to end the breast cancer epidemic.* And among BCA's core values is a commitment to the structural changes in society that are necessary to accomplish our mission.

BCA has changed in more tangible ways, too, over the past ten years. The board of directors has developed from a small group of white, mostly middle-class women to one of 14 women from diverse backgrounds, nearly half of whom are women of color. The organization has grown from a volunteer-run group to a paid staff of eight, and the organization's budget has tripled in the past five years alone. The *BCA Newsletter*, which started as a two-page photocopied sheet, is now mailed to more than 8,000 individuals and institutions and is widely regarded as a leading source of information about breast cancer issues. BCA's Web site serves as a valuable source of information and a link to activism for individuals with computer access around the world.

Thousands of members around the world now carry on the legacy of BCA's founders, pushing the medical community and policymakers for answers and change. And by continuing to develop the infrastructure of the organization, BCA ensures that it will be around for as long as it takes to end the breast cancer epidemic.

**“We are not makers of history.
We are made by history.”**

—Martin Luther King, Jr.

THE HISTORY OF BCA

1990

The first BCA meeting is held in founder Elenore Pred's living room. “We are meeting to organize BREAST CANCER ACTION,” the first flyer announced. “Our goals are education and political action to prevent a further rise in breast cancer.”

The incidence of breast cancer in the United States has risen every year since 1990, as it did for 50 years before. About 150,000 women were diagnosed with the disease in 1990; in 2000, an estimated 182,800 were diagnosed. BCA now works with organizations and individuals across a wide political spectrum on policy changes to ultimately stem the rising tide of breast cancer.

1991

BCA founders Elenore Pred, Susan Claymon, and Belle Shayer, along with other breast cancer activists, meet with the director of the National Cancer Institute to demand that the agency address the breast cancer epidemic. Claymon becomes the first breast cancer activist to address the President's Cancer Panel, a group of advisors appointed by the president of the United States to appraise the National Cancer Program.

Elenore Pred died of metastatic disease in October of 1991. In January 2000 Susan Claymon died of metastatic breast cancer after a 15-year battle with the disease. Belle Shayer, the only surviving founding board member of BCA, continues to serve on the organization's board of directors. At every moment of loss, women have stepped forward to lead BCA with the same commitment, courage, and passion shown by the founders.

1992

BCA convenes the first public breast cancer activist forum for the San Francisco Bay Area community, sponsored by the Junior League of San Francisco.

In 1997 BCA sponsored its own organizing meeting for breast cancer activists, featuring former U.S. Surgeon General Joycelyn Elders as keynote speaker. Five activist task forces—focusing on media, legislation, direct action, community outreach, and treatment issues—were launched at the meeting. BCA's task forces continue to form the core of BCA's program work, and BCA's Town Meeting has become an annual event attended by hundreds of activists.

1993

BCA helps draft and enact into law California's Breast Cancer Act, which raises money for screening and research, and guarantees that advocates will participate in decisions about the type of research that is funded.

BCA members continue to serve on the governing council for this program, which provides \$17 million in funding each year for breast cancer research. The Breast Cancer Act was also used as a model for the national Department of Defense Breast Cancer Research Program, an innovative program that funds a wide portfolio of breast cancer research and actively solicits advocates' input – including that of BCA members, who serve on its peer review panels.

1994

BCA testifies before the Food and Drug Administration in opposition to resuming the “breast cancer prevention trial,” a study of the drug tamoxifen in healthy women, because of reports of deaths from uterine cancer in the trial.

While the informed consent requirements of the trial were changed, the study was allowed to resume despite the objections of BCA and other women's health organizations. And despite serious questions raised by BCA about the data from the trial and the dangers of tamoxifen for healthy women, the FDA in 1998 approved the use of tamoxifen for breast cancer risk reduction in women who have not been diagnosed with the disease but are considered to be at high risk. At BCA's urging, the agency denied the drug manufacturer AstraZeneca the right to refer to tamoxifen as a “preventive” for breast cancer. Meanwhile, tamoxifen was added to the federal government's list of known carcinogens in 2000, and BCA launched a coalition of women's health organizations that have declared their independence from pharmaceutical funding to counter direct-to-consumer advertising of pills for the “prevention” of breast cancer.

1995

BCA becomes a founding member of the Toxic Links Coalition, a group of organizations making the link between health and the environment. The Coalition organizes and leads the first annual Cancer Industry Tour of the corporate headquarters of companies whose practices contribute to the cancer epidemic.

In 2000, BCA assisted the Women's Cancer Resource Center in Minneapolis in putting together the first Cancer Industry Tour in that city, which followed the model set by the Toxic Links Coalition.

1996

In testimony before a committee of the United States Senate, BCA calls for “one-stop shopping” for information on cancer clinical trials, modeled on centralized trial information for AIDS.

A year later, BCA's demand became law — and, by 1999, the clinical trials database was up and running at www.cancer.net.nci.nih.gov.

1997

Citing the absence of evidence that routine mammography screening reduces breast cancer deaths for women ages 40 to 49 — and noting the risks of screening, including radiation exposure and false negative and false positive results — BCA publicly opposes the call by the National Cancer Institute, the American Cancer Society, and other cancer charities for routine mammograms among women in this age group.

The results of a major Canadian study released in 2000 showed that among women in their fifties, yearly mammograms coupled with annual, thorough clinical breast exams are no more effective than physical breast exams alone at reducing the risk of dying of breast cancer. BCA urges policymakers to devote more time and money toward training women and doctors in effective physical breast exam techniques, and continues to call for finding more effective, radiation-free technologies for breast cancer detection that work for all women.

1998

BCA becomes the first national breast cancer organization to adopt a policy explicitly prohibiting the organization from accepting financial support from corporations, such as pharmaceutical companies and corporate polluters, that are known or suspected to profit from the cancer epidemic.

BCA continues to be the only national breast cancer organization to maintain such a policy. The decision was featured in a lead article in the Journal of the National Cancer Institute and continues to be a focus of debate in the cancer community. Other regional breast cancer organizations have followed BCA's lead by adopting similar policies.

The United States Postal Service issues the first-class breast cancer research stamp — the first part-postal, part-charity postage stamp — for a two-year run. Thirty percent of the funds raised by the stamp supports the Department of Defense Breast Cancer Research Program, while the remaining 70 percent goes to the National Cancer Institute. BCA unsuccessfully urges legislators to direct the latter 70 percent to the National Institute of Environmental Health Sciences (NIEHS), where it would be used to investigate the causes of breast cancer and could lead to the prevention of the disease.

The stamp program, which expired in 2000, was reintroduced for another four years. Despite pressure from BCA activists, legislators again refused to redirect part of the funds to the NIEHS. But increased funding for the NIEHS and research into the environmental links to breast cancer is now the focus of growing attention both in Congress and among the activist community.

1999

BCA launches its Spanish-language information project, *Saber Es Poder* (Knowledge Is Power), with the first edition of a Spanish language newsletter.

Saber Es Poder is now published quarterly and distributed free of charge to organizations serving the Spanish-speaking community.

Several BCA staff and volunteers head to Atlanta to attend the annual meeting of the American Society of Clinical Oncology, the largest international scientific meeting of the year focused on cancer. Their presence at the conference ensures that the voices of people living with breast cancer are heard by the medical and research communities.

BCA representatives continue to attend oncology conferences and gain media attention around the country. This work is supported by the Susan Claymon Advocacy Fund, established after the death of BCA's cofounder, to sustain advocacy work outside of the San Francisco Bay Area.

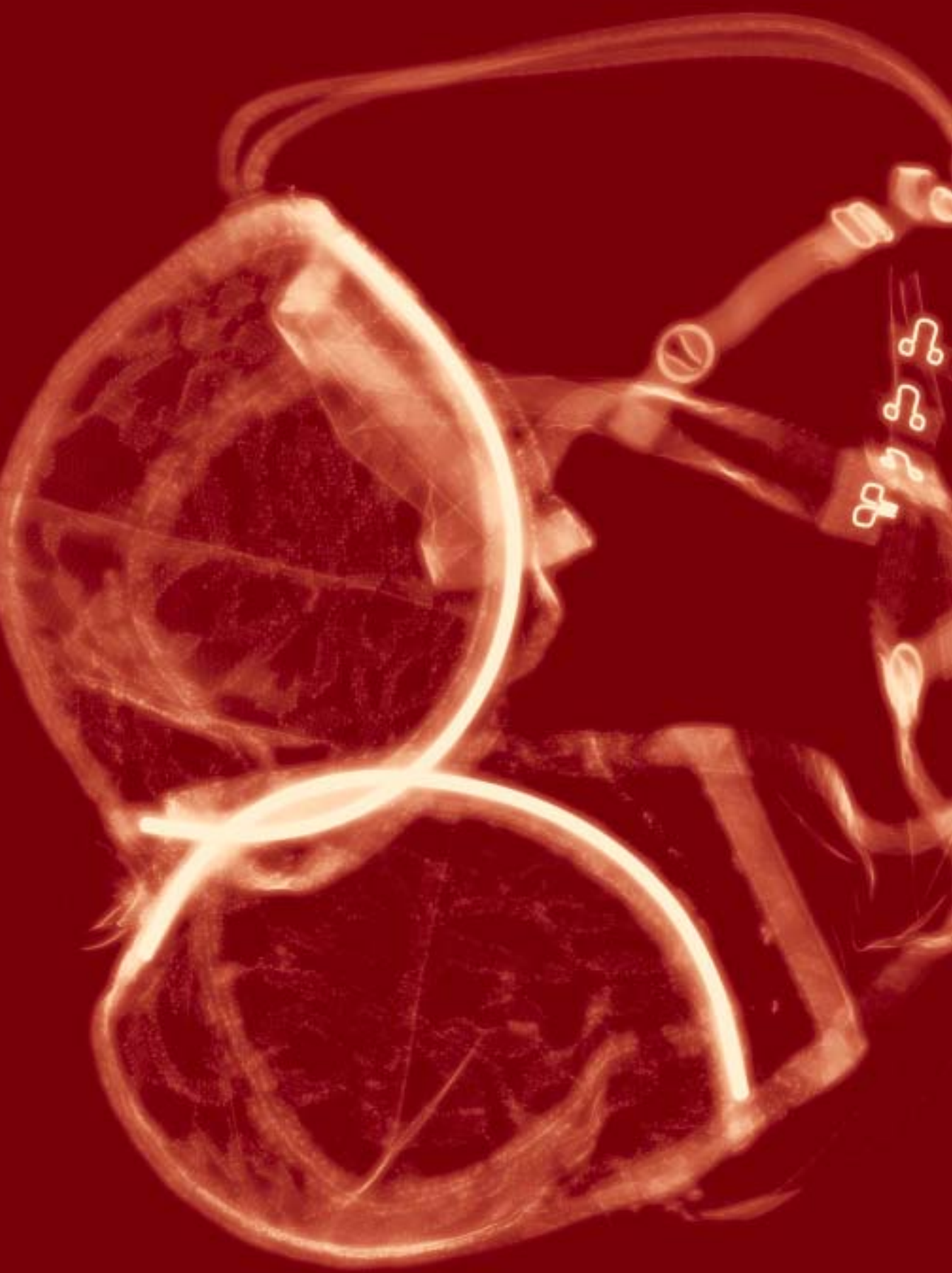
2000

BCA marked its tenth anniversary in the year 2000.

In commemoration of our tenth year of activism — and in our ongoing effort to get the public to think differently about the breast cancer epidemic — BCA commissioned a theatrical civil action, or street-theater piece, capable of being reproduced by activists around the country as an educational and organizing tool.

The theater piece, like all of BCA's work, acknowledges the social, political, medical, and personal realities of breast cancer while inspiring people to create change. BCA's goals are reflected in our work toward **true breast cancer prevention** achieved by understanding and eliminating the causes of the disease, a **true cure** with treatments that don't nearly kill patients or cause other diseases, and **universal access to quality health care**.

To these ends, BCA launched two new campaigns in 2000 — **Stop Cancer Where It Starts** and the **Rachel Carson Project** — and continued our efforts on other fronts to reach a future in which real prevention is possible and effective care is available to all who need it.



STOP CANCER WHERE IT STARTS

This year, in collaboration with other environmental and women's health organizations, BCA urged the public to reclaim October as "Stop Cancer Where It Starts" month.

As most breast cancer activists know too well, October has been co-opted by corporate interests as "Breast Cancer Awareness Month," filled with propaganda and misinformation about the breast cancer epidemic. Ads and articles in women's magazines admonish readers to schedule annual mammograms, while pink ribbons sprout everywhere to indicate awareness of the disease. Because the principal corporate sponsor of "Breast Cancer Awareness Month" is the AstraZeneca corporation — which manufactures the breast cancer drug tamoxifen, holds controlling interest in a chain of cancer treatment centers, and, until recently, manufactured pesticides known to cause cancer — the public rarely hears a word about true cancer prevention and environmental links to the disease during this October publicity blitz.

As part of BCA's continuing work with other women's health and environmental organizations, we worked this year with legislators in the cities of San Francisco, Berkeley, and Oakland, California, to pass resolutions declaring October "Stop Cancer Where It Starts" month instead. These resolutions acknowledge the health impact of toxins released into the environment and pledge to reduce them.

We also began taking the Stop Cancer Where It Starts campaign beyond the San Francisco Bay Area, training other community activists and giving them the information and tools necessary to push for the passage of local government resolutions aimed at eliminating the release of toxic substances in their communities. In October, BCA placed a full-page advertisement in the western edition of the *New York Times*, urging its more than 100,000 readers to work with their local legislators to initiate such resolutions and to stop cancer where it starts. The Stop Cancer Where It Starts campaign is based on the belief that by organizing at the local level, communities can work to create a future free of breast cancer.

THE RACHEL CARSON PROJECT

BCA presented the Rachel Carson Project in 2000 to stimulate public thinking about the problems with the structure of the existing breast cancer research agenda — and to offer an innovative way to revamp it in the future.

Breast cancer research is currently carried on by a vast array of public and private entities, including pharmaceutical companies, private foundations, research hospitals, academic institutions, and state and federal government agencies. But the fragmentation of the research agenda is not the only thing keeping us from making greater progress in the war against cancer. Breast cancer research is funded in small increments, forcing scientists to work to renew their grants rather than to focus on the disease they are studying.

The Rachel Carson Project — named for the scientist who drew our attention to the dangers of pesticides before she succumbed to breast cancer in 1964 — is BCA's proposal for a coordinated research strategy in which patients, activists, doctors, and scientists join together to create a new breast cancer research plan.

Modeled on the Manhattan Project, an effort that relatively quickly solved the challenge of the "need" for an atomic bomb, the Rachel Carson Project calls for all of the money now devoted to breast cancer research to be pooled and reallocated to several research centers around the country. The centers would be staffed with the best scientists now working on issues that are or might be related to breast cancer treatment and prevention, representing a wide range of disciplines. And the centers would be funded until one or more of them produced effective treatments for breast cancer that are not systemically toxic, as well as



an understanding of the causes of breast cancer, which would enable us to take steps to prevent the disease.

Almost daily we hear news reports about the promise of advances in breast cancer treatment, but the fact is this: The vast majority of women diagnosed with breast cancer this year will be faced with essentially the same treatment choices — surgery, radiation, and chemotherapy — that women faced nearly 30 years ago, when then-president Richard Nixon first declared a “war on cancer.” Only by restructuring the research agenda will we ever be able to move from a present filled with military analogies to a future with effective, pinpointed treatments and the promise of true breast cancer prevention.

ACCESS TO QUALITY HEALTH CARE

BCA has long been at the forefront of efforts to ensure that women of all income levels have access to quality care. For years women who were too poor to afford private insurance but were ineligible for Medicaid could be screened for breast and cervical cancer through state programs, but they could not receive treatment except through private charity — a public health policy that was both unconscionable and unethical.

BCA has worked to see that women screened through government programs receive quality, comprehensive health care if they are diagnosed with cancer. This year BCA successfully urged Congressional representatives to approve a federal bill that provides treatment funding for low-income women diagnosed with breast or cervical cancer.

On the state level, as a member of the California Breast and Gynecological Cancer Treatment Task Force, BCA helped persuade California governor Gray Davis to include in his 2001 budget \$20 million for the treatment of women diagnosed with breast cancer at state expense. But while this step was important, it was not enough: it provided treatment for breast cancer only, and it did so through a nonprofit agency not integrated into the state's health care system. BCA continues to work to broaden the state's treatment program and to integrate it with the state's health care program.

Through efforts to develop the policy analysis and grassroots advocacy strategies necessary to create government-funded, broad-based treatment programs, BCA helps open the door to a future of universal access to quality health care.

FOLLOWING THE MONEY

Many millions of dollars are now raised each year to advance “the fight against breast cancer.” Nonprofit agencies and corporations alike raise funds through a variety of activities, including walks, runs, and mountain climbs. BCA pushed forward in 2000 with its effort to follow the money flooding into the cause by launching a new campaign, “Think Twice Before You Walk,” to encourage the public to be thoughtful about participating in or supporting fund-raising activities such as the Avon Breast Cancer 3-Day walk, currently the largest event of this kind.

Through commentaries in national publications and on public radio, we spread the word about how the money for many fund-raising events is both raised and spent, and we urged the public to give directly to breast cancer organizations if they shared our concerns. We also created and distributed brochures explaining the funding practices of activities like the Avon 3-Day and describing how individuals can work to change those practices. On a similar issue, prompted by widely circulated e-mails urging recipients to follow links to a Web site and “click for the cure,” we developed an electronic reply to e-mail to



senders of these messages, explaining why finding a cure for breast cancer will never be that simple.

As public concern about the most common cancer in women increases, so does the amount of money raised in the name of the cause. By investigating and exposing the ways in which these funds are raised, BCA works to ensure that they will be spent on efforts that will bring us closer to ending the breast cancer epidemic.

COUNTERING "PILLS FOR PREVENTION"

While billions of dollars are being spent in the search for a cure for breast cancer, the effort to prevent the disease is finally getting attention as well. However, much of this attention on prevention is directed toward an appealing but limited and risky approach of "pills for prevention" rather than toward a primary prevention approach that would address the causes of breast cancer, especially environmental links to cancer.

In the face of multimillion-dollar advertising campaigns to promote potentially dangerous pills as breast cancer "prevention" to healthy women, BCA worked to let the public know that there is another approach: the precautionary principle of public health, sometimes phrased as "first, do no harm."

To shift attention away from drugs and toward the precautionary principle, BCA launched Putting People First, a coalition of women's health organizations devoted to promoting true prevention as the ability to identify and eliminate the environmental causes of breast cancer. The coalition develops and tests strategies to inform people about the dangers of breast cancer "prevention" pills, highlights the problems associated with treating a risk factor as though it is a disease, and promotes greater awareness of the precautionary principle of public health.

Putting People First has met with and presented testimony to the Food and Drug Administration, and through it BCA will continue to bring and expand on our concerns to appropriate federal agencies. We will continue our work with the media to get the message out to the public that it is time for a new approach to cancer prevention, one that puts the public's health before corporate profit.

ACCESS TO RELIABLE INFORMATION

This year BCA staff responded to more than a thousand telephone calls and written requests for information on a myriad of issues connected to breast cancer. BCA's bimonthly newsletter, which is distributed to more than 8,000 individuals and institutions (a 30 percent increase from last year), included coverage of controversial issues such as digital mammography, high-dose chemotherapy, and breast implant safety, along with book reviews, member profiles, and reports from international oncology conferences.

BCA's Web site (www.bcaction.org) entered the future in 2000 when it underwent a spectacular renovation, giving users access to a wide range of information about BCA's work more easily and thoroughly than ever before. Visitors to the site can now search an archive of past newsletters by topic, date, or keyword; sign up to volunteer with BCA; find out more information about BCA's campaigns; get the answers to frequently asked questions about breast cancer; make a donation to support BCA's work; and much more.

By keeping up with rapidly changing information and technology, BCA empowers thousands of individuals to become involved in their own treatment decisions and to join us in working to end the breast cancer epidemic.

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COMMUNITY ORGANIZING

BCA's five activist task forces — built on the idea that everyone can do something that matters about the breast cancer epidemic — continued to be fueled this year by the energy of hundreds of volunteers.

Across the nation, members of BCA's Media Response Task Force responded to radio, TV, newspaper, and magazine stories that in some way or another missed an important point about breast cancer. With help from talking points prepared by BCA, task force members wrote letters on such topics as the Avon 3-Day walk, the limitations of mammography, and a study designed to test the effects of a toxic rocket fuel compound by having human volunteers ingest it.

Guided by BCA policy positions and sample letters, Legislative Action Task Force members communicated their views to both state and federal representatives on a number of issues, including breast and cervical treatment funding, the use of toxic waste in fertilizer, and a right-to-know law on the use of pesticides on school grounds.

Members of BCA's Treatment and Scientific Issues Task Force attended national oncology conferences, actively participating in conference discussions of some of the critical issues in breast cancer treatment and research and reporting back to BCA members through workshops and newsletter articles.

Community Outreach Task Force members attended events throughout the San Francisco Bay Area to provide information about breast cancer. Our presence at neighborhood health fairs, outdoor fund-raisers, Earth Day festivals, and college campuses helped to bring BCA's message to new audiences.

Members of BCA's Audre Lorde Action Brigade were called to the streets throughout the year, to protest the U.S. Navy's refusal to clean up a San Francisco shipyard after a toxic fire, attend a public hearing on a proposed floating power plant in the San Francisco Bay, gather signatures for a petition to save San Francisco General Hospital's breast clinic, and demonstrate against a medical waste incinerator in a low-income Bay Area community of color.

Audre Lorde, a social activist and writer who envisioned an "army of one-breasted women" descending on Congress to demand change, died of breast cancer in 1992 at age 58 — but her spirit lives on in the women and men of BCA's direct action contingent.

"We've got to stay in their faces," Elenore Pred declared a decade ago. She cited the key to the success of the AIDS activists after whom BCA was modeled: "They had somebody constantly making the politicians know that there were people behind the statistics."

Ten years later, through all of its work, BCA continues to carry the voices of people affected by breast cancer to inspire and compel the changes necessary to end the breast cancer epidemic. We stand at the forefront of the breast cancer movement, demanding honest information and meaningful answers — and we will do so for as long as it takes. The future is in our hands.

BCA SUPPORTERS MAKE THE DIFFERENCE

Breast Cancer Action's work is made possible by the generosity of supporters who believe that, by developing programs that honor the vision of the organization's founders, we can effect the changes necessary to end the breast cancer epidemic. We gratefully acknowledge the financial assistance of all of our supporters, including the people and institutions listed below, whose contributions allow BCA to work to create a future in which breast cancer prevention and universal access to quality care are our reality.

\$10,000 - \$75,000

Allegro Dancers • The Beldon Fund • The California Endowment • The Joseph Down Foundation • The Gaea Foundation • The Jessie Smith Noyes Foundation • Universal Care • Wells Fargo Foundation

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Natalie and Stephen Compagni Portis • Vivian L. Schneider • Margaret Storkan, M.D.

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\$250 - \$499

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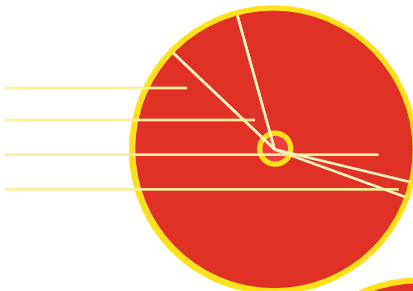
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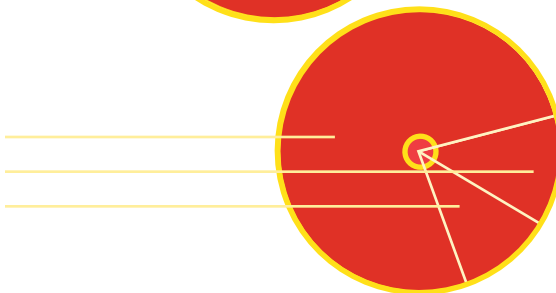
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REVENUES	AMOUNT	% OF TOTAL
Individual contributions	\$434,885	56.6%
In-kind gifts	65,803	8.6%
Foundation Grants	254,150	33.1%
Other Revenue	13,523	1.8%
Total Revenue	\$768,361	100.0%



EXPENSES	AMOUNT	% OF TOTAL
Program	\$476,981	76.5%
General support	78,692	12.6%
Fundraising	68,073	10.9%
Total Expenses	\$623,746	100.0%



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