



BREAST CANCER ACTION A CLEAR VOICE

ANNUAL REPORT 1998

MISSION

Breast Cancer Action carries the voices of people affected by breast cancer to inspire and compel the changes necessary to end the epidemic. Our core values are:

- We are a membership-based organization.
- We honor each person's commitment and energy to our mission.
- We are not afraid to examine all sides of all issues.
- We cannot be bought.
- We tell the truth about what we discover.
- We serve individuals while reaching the broader population.
- We value the involvement of grassroots activists throughout the country and around the world to further our mission.
- We encourage people to participate fully in decisions relating to breast cancer.
- We believe access to information is vital.
- We recognize that structural changes in society are needed to accomplish our mission.

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IN HONOR

This annual report is dedicated to Susan Claymon, one of BCA's founders, who has served on the board of the organization from its beginning in 1990.

Susan is an inspiration to thousands of women each year who hear the dreaded words, "You have breast cancer." Diagnosed more than a decade ago with breast cancer so advanced that she was told to get her affairs in order, Susan became a breast cancer activist instead. Whether a woman is newly diagnosed or struggling with decisions about treatment of metastases, Susan is available to lend a thoughtful and compassionate ear and wise counsel. When she is not helping individual women, Susan works to highlight the environmental links to cancer and promote the precautionary principle of public health, encouraging the use of environmentally-safe alternatives to ways of doing business that we know—or have reason to believe—are harmful to human health. Susan's energies and commitment are a model for everything we do at Breast Cancer Action.



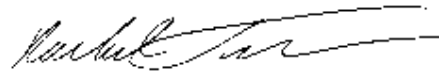
INTRODUCTION

Thanks to the dedicated work of thousands of activists, there is now much more attention paid to breast cancer, the most common cancer in women. But at the center of the breast cancer epidemic, sometimes it feels as though the noise level has become almost deafening. From the hype about the latest “cure” for cancer (in mice) to the brouhaha about pills that “prevent” breast cancer, we are inundated with information. In the midst of the press reports, legislative activity, and scientific studies focused on breast cancer, people look to Breast Cancer Action for clear information that is not easily found elsewhere and for thoughtful analysis about the politics of breast cancer.

This report of our 1998 activities shows how much has been accomplished and how far we have to go before true prevention and real cure become realities. Thanks to Breast Cancer Action, more people understand that everyone can do something that will make a difference in the breast cancer epidemic. More people understand that breast cancer occurs in a social, political and economic context that must be addressed if the problem is to be solved. And more people understand that effective action to end the breast cancer epidemic requires the clear voice and leadership that Breast Cancer Action provides.

We know, too, that clarity can bring conflict. But our experience inspires us to believe that Breast Cancer Action is on the right track. That inspiration comes from the support of the people who make our work possible.

Our clear voice is reaching new ears because of the individuals, foundations, and businesses whose generosity supports us. Our work in 1998 is recounted in the pages that follow because, by reflecting on our past, we make our future more certain. We are honored by and profoundly grateful for the support that allows Breast Cancer Action's clear voice to be heard.



Rachel Morello-Frosch
President



Barbara A. Brenner
Executive Director

A CLEAR VOICE IN EDUCATION AND INFORMATION

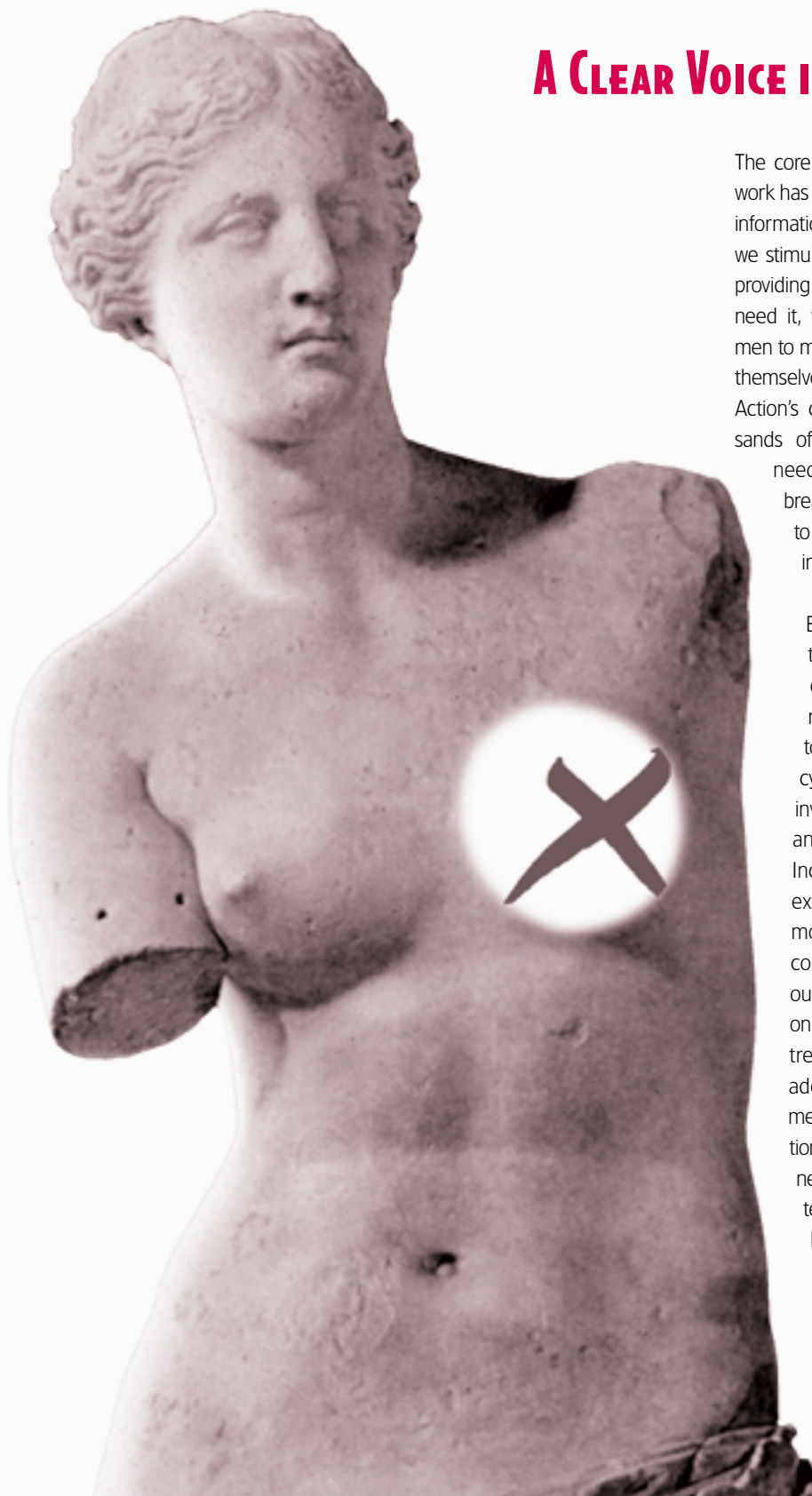
The core of Breast Cancer Action's work has always been education and information. By educating the public, we stimulate people to activism. By providing information to those who need it, we empower women and men to make informed decisions for themselves. In 1998, Breast Cancer Action's clear voice reached thousands of people who wanted or needed information about breast cancer, or who wanted to become involved in working to end the epidemic.

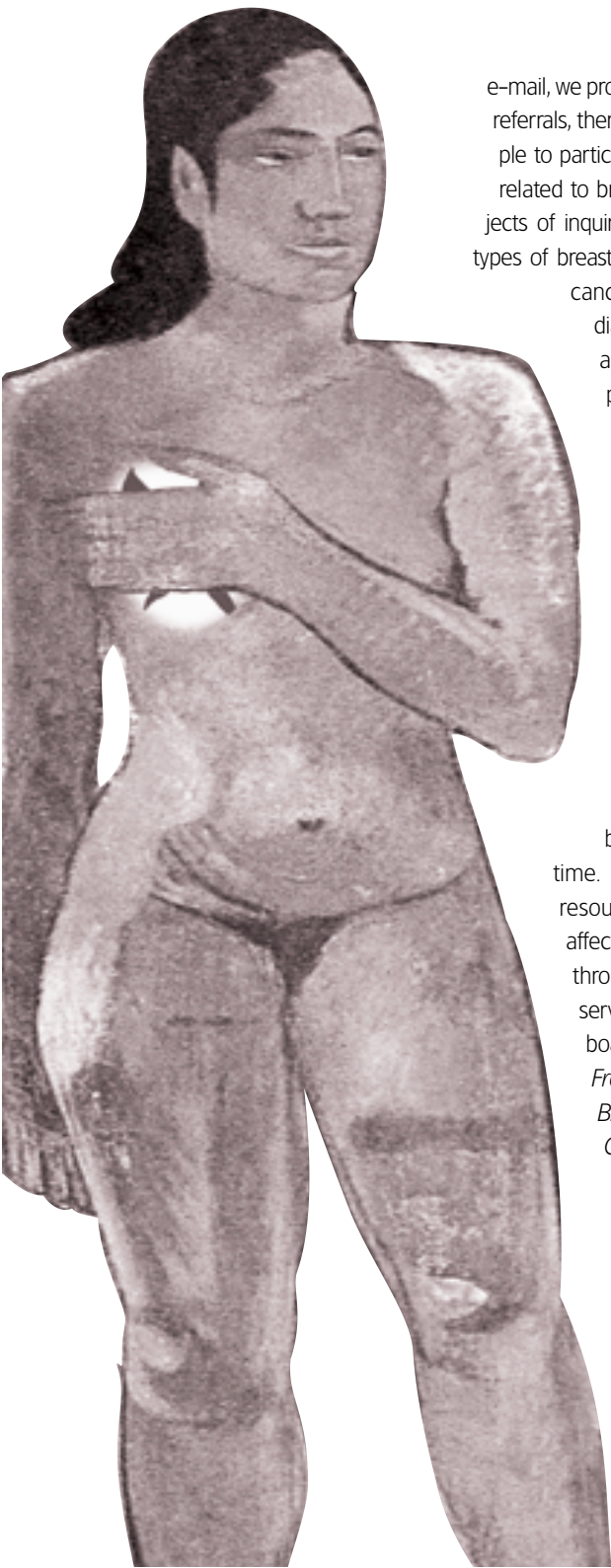
Because access to information is vital, a new Web site design (www.bcaction.org) makes it easier for people to find BCA's information in cyberspace and to become involved with our work from anywhere in the world. Included on the site are excerpts from BCA's bi-monthly newsletter, widely considered the most thorough source of information on breast cancer diagnosis, treatment, and politics. In addition to informing BCA members about policy positions taken by the organization, newsletter articles, most written by women living with breast cancer, covered topics including: tamoxifen for the treatment of breast cancer, decisions about chemotherapy, reports from scientific and clini-

cal meetings on breast cancer, pills for breast cancer "prevention," advances in mastectomy surgery, legislative activity, profiles of activists, book reviews, new treatments for metastatic disease, compassionate access to treatment, genetic tests, the Ward Valley radioactive waste dump, organic food standards, sentinel node biopsy, hydrazine sulfate, CoQ-10, media analysis, electromagnetic fields, and access to treatment. Our newsletter distribution increased by 35% to more than 4700 individuals and institutions in 1998, and we granted numerous requests to reprint newsletter articles.

Saber es Poder (Knowledge is Power), our Spanish-language project, was launched in 1998 with a premier newsletter issue about the benefits and risks of tamoxifen in the treatment of breast cancer. Telephone assistance for Spanish speakers also became available through Saber es Poder. BCA provides information and referral assistance to individuals, for themselves or their loved ones, who are struggling with the many difficult decisions that are triggered by a breast cancer diagnosis. With the addition of a new toll-free number (1-877-2STOPBC / 1-877-278-6722), we made it possible for people from all over the country to reach us, and they did.

From Marin to Malta, from Bangor to Bakersfield, by phone, fax, letter, and





e-mail, we provided information and referrals, thereby encouraging people to participate fully in decisions related to breast cancer. The subjects of inquiries in 1998 included: types of breast problems and breast cancer; detection and diagnosis; conventional, alternative and complementary treatment; resources; statistics; risk; and the politics of breast cancer.

Consistent with our commitment to serving individuals while reaching the broader population, BCA also participated in activities that reached large numbers of people at one time. We helped provide resources for people affected by breast cancer through activities such as serving on the advisory board of the *Third San Francisco Bay Area Breast Cancer Resource Guide* and participat-

ing on an Internet list for breast cancer resource organizations. We gave the public a beautiful yet disturbing look at the realities of breast cancer by coordinating the Art.Rage.Us project, which presented the art and outrage of breast cancer from the perspective of women living with the disease.

BCA also encouraged the general public to learn about the realities of breast cancer and to recognize that structural changes in society are needed to end the epidemic. In partnership with other cancer and environmental health organizations, BCA led the 1998 Cancer Industry Tour in San Francisco, visiting environmental polluters, public relations firms, and the offices of the American Cancer Society—the largest cancer charity in the country—to help people understand the link between corporate profit and the cancer epidemic. To commemorate October as Breast Cancer Industry Month, BCA placed a full-page advertisement in the west coast edition of the *New York Times*, exposing one of the top 25 censored stories of the year—the cor-

porate interest behind Breast Cancer Awareness Month—and demanding research into the causes of breast cancer.

BCA reached out to people in the communities where they live and work, providing them with information about breast cancer. If information was needed or useful, Breast Cancer Action was there. From BCA's own forum, "Angry? Who's Angry? The Politics of Breast Cancer," to presentations to the Junior League of Oakland and the East Bay, to the South Bay Black Nurses Association, Breast Cancer Action provided information at over 30 venues in 1998.

A CLEAR VOICE IN POLICY ADVOCACY

The goals that must be achieved for BCA to accomplish its mission are clear: true prevention through understanding and eliminating the causes of breast cancer; true cure with treatments that don't nearly kill people or cause other diseases, and universal access to quality healthy care. As a matter of policy in pursuing these goals, we are committed to the precautionary principle of public health: first, do no harm. BCA works with other organizations to encourage the use of environmentally-safe alternatives to ways of doing business that we know—or have reason to believe—are harmful. In 1998, we made significant progress on a number of policy fronts related to these goals.

PREVENTION AND THE PRECAUTIONARY PRINCIPLE

Because breast cancer is actually many diseases, both its cure and prevention will be difficult to achieve. Breast Cancer Action believes that the key to preventing breast cancer will ultimately come from understanding and eradicating the causes of the disease. But the difficulties of understanding breast cancer are aggravated by the political and economic context in which the epidemic has evolved. The first step to changing these realities is to understand them, and Breast Cancer Action took several steps in 1998 to promote public understanding of the barriers to achieving true breast cancer prevention.

We became the first breast cancer organization to adopt a policy limiting the types of corporate enterprises from which we will accept funds. As featured in a lead news story in the *Journal of the*

National Cancer Institute, BCA's policy clearly states that in order to avoid even the appearance of a conflict of interest, we will not accept financial support from companies that provide cancer treatment or health insurance, are engaged in cancer research, or are known to contribute to environmental contamination. The policy, which has since been adopted by several local and regional breast cancer organizations, conveys the message that BCA cannot be bought, that we are not afraid to examine all sides of an issue, and that we stand with our allies in the environmental justice movement to make the link between cancer and the environment.

BCA's corporate contributions policy is also a tool for educating the public about the corporate connections to breast cancer. In 1998, BCA was a key participant in "Profit\$ and Lo\$\$e\$," a Boston conference on the political and economic context of breast cancer research which dealt at length with corporate conflicts of interest and how they affect what is—and isn't—studied in breast cancer.

The same clear-eyed view of the way things are connected led BCA to take a public stand in opposition to "The March" against cancer, which was spearheaded by prostate cancer survivor General Norman Schwarzkopf. BCA opposed the march because General Schwarzkopf was a key figure in the U.S. government's exposing thousands of veterans to toxic substances during the Gulf War and in covering up that exposure when many veterans became desperately ill.



When General Schwarzkopf was confronted with BCA's concerns on NBC's "Today" show, he urged viewers to ignore his public role in the war and focus instead on his private concerns about cancer.

And we took the message of the precautionary principle to the National Breast Cancer Coalition's Environmental Policy Summit.

BCA made strides in encouraging a revamping of the breast cancer research agenda to address causes of the disease. Working with the federal Office of Women's Health, BCA was a key participant in a national conference on areas of high breast cancer incidence. The conference brought together activists and researchers from around the country to develop new strategies for studying geographic regions with a high incidence of breast cancer.

We urged our members, the general public, and our federal legislators to work to direct some of the funds

from the semi-postal breast cancer stamp toward understanding the environmental causes of breast cancer.

Proving our commitment to tell the truth about what we discover, BCA stood alone among American breast cancer organizations in criticizing the early termination of the Breast Cancer Prevention Trial of tamoxifen in healthy women and in successfully urging the Food and Drug Administration (FDA) to refuse to allow Zeneca, the manufacturer of tamoxifen, to market the drug to healthy women as "prevention."

As a founding member of Health Care Without Harm, we worked with other organizations to eliminate the nonessential incineration of medical waste and to promote the use of safe materials and treatment practices in the medical profession.

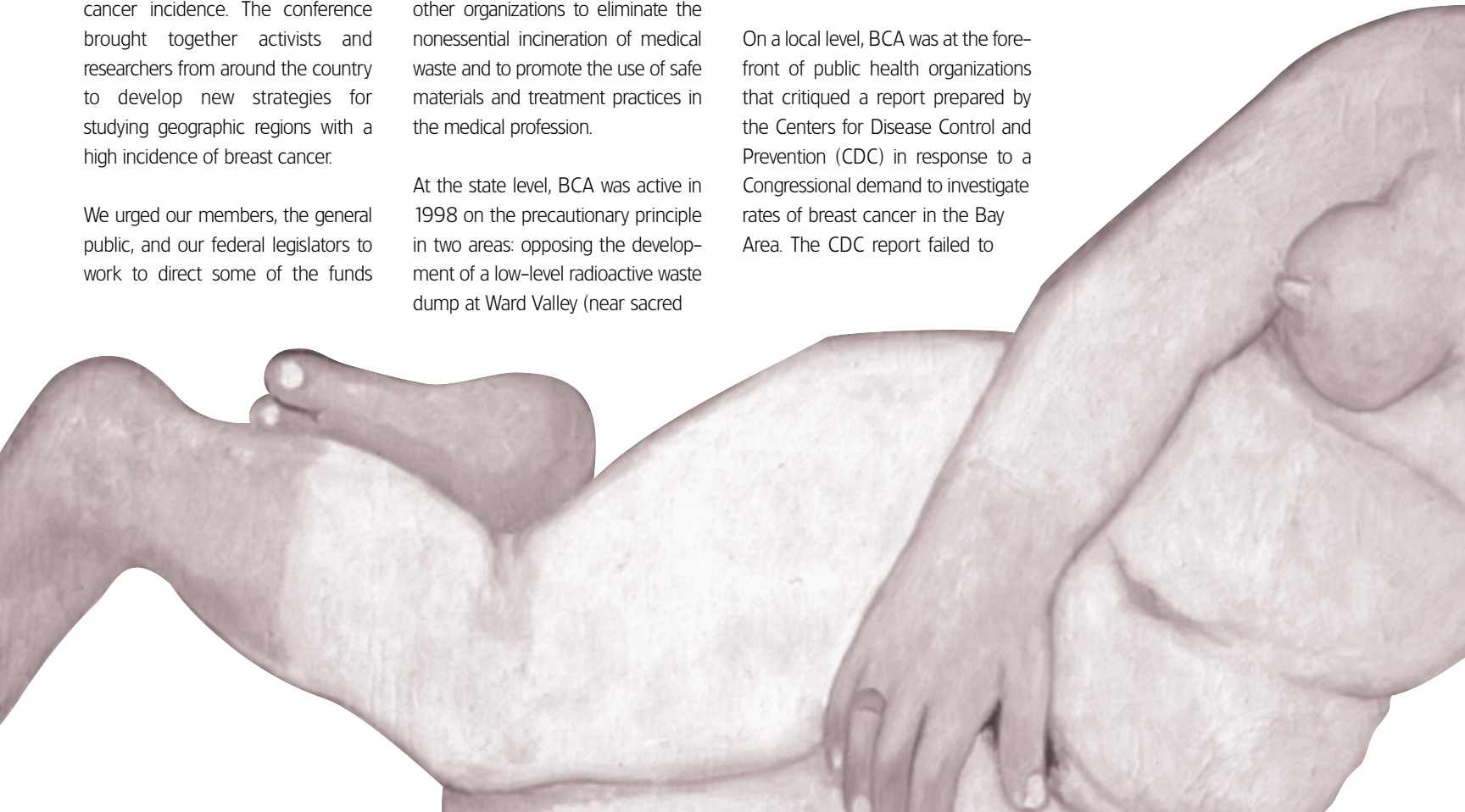
At the state level, BCA was active in 1998 on the precautionary principle in two areas: opposing the development of a low-level radioactive waste dump at Ward Valley (near sacred

lands of indigenous people and near the Colorado River watershed), and advocating reduction of pesticide use in California. In collaboration with environmental justice organizations and the Native American community, we helped to stave off the development of the Ward Valley dump for another year, with promising signs that the site will be permanently protected. As a core member of Californians for Pesticide Reform, we participated in the campaign to end the use of methyl bromide in California and in the School Pesticide Right to Know campaign to require prior disclosure of the use of pesticides in the vicinity of California schools.

On a local level, BCA was at the forefront of public health organizations that critiqued a report prepared by the Centers for Disease Control and Prevention (CDC) in response to a Congressional demand to investigate rates of breast cancer in the Bay Area. The CDC report failed to

look closely at the rates and patterns of breast cancer in the Bay Area, and thereby failed to provide any useful guidance on steps that might be taken to evaluate and ultimately eliminate the causes of breast cancer. BCA submitted comments in response to the CDC report and worked with California Congressional representatives to address the problems it posed.

BCA successfully urged the City of Oakland to adopt a resolution on dioxin, health, and environmental justice, and the City and County of San Francisco to adopt an integrated pest management program for public lands.



ADVANCING TOWARD CURE

In 1998, we saw, for the first time in many years, the approval of a new kind of treatment for breast cancer, and Breast Cancer Action helped make it happen. Herceptin®, manufactured by Genentech, attacks the overproduction of the Her2/neu protein without attacking every fast-growing cell in the body. As a result,

it shows the potential for treating breast cancer without the dire side effects of existing chemotherapy treatments. The drug does not benefit everyone with breast cancer, and the benefits, which are relatively short-term, are maximized by using the treatment in combination with chemotherapy. But the advance that Herceptin represents would not have been possible without the efforts of Breast Cancer Action to bring the treatment to trial and to make it available on a compassionate access basis to those ineligible for the trial. These efforts helped to stimulate rapid approval of Herceptin by the FDA.

At both the federal and state levels, BCA members participated in directing research toward more effective treatment of breast cancer. Through BCA's role on the California Breast Cancer Research Council and our participation in peer review for the California program and the Department of Defense Breast Cancer

Research Program, we made sure that the perspective of breast cancer advocates was heard as decisions were made about the future direction of breast cancer research.

ACCESS TO CARE

In a society that focuses much of its attention on scientific and technological advances against disease, we often lose track of the difficulties that many people face in gaining access to even basic services. Addressing these problems is an important aspect of Breast Cancer Action's commitment to universal access to care. In 1998, BCA's work in this area took on a number of aspects.

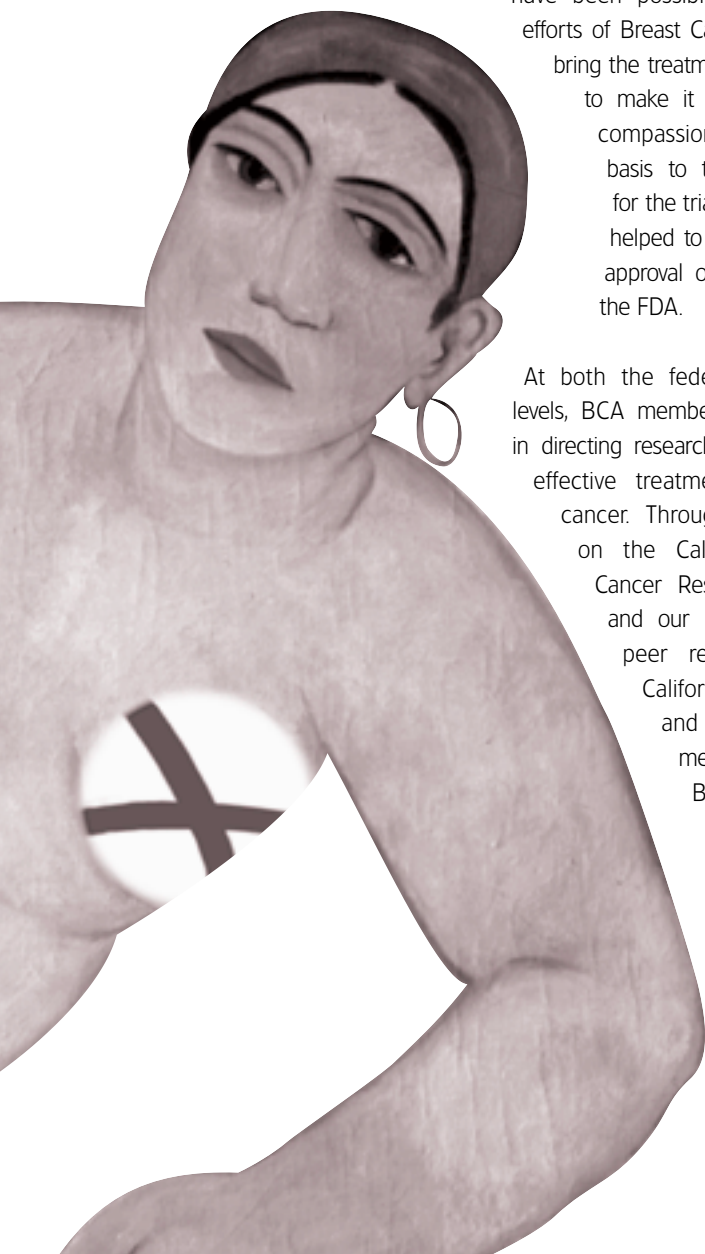
Using our ability to bridge many communities, BCA was the sponsor of initial efforts to address the absence of practical support services for women with cancer. With the visionary support of the Richard and Rhoda Goldman Fund, BCA facilitated the beginning of a long-range planning effort to develop a model for the delivery of support services for women with breast cancer and other cancers. At the state level, BCA was a leader in the so far unsuccessful campaign for state-

funded treatment for women diagnosed with breast cancer through California's Breast Cancer Early Detection Program.

Addressing one of the many dilemmas associated with managed care, BCA argued on behalf of breast cancer patients in urging the California Supreme Court to limit an insurance company's power to terminate a doctor from its preferred provider list. We addressed the implications of using genetic testing in insurance underwriting at a conference on controversies in insurance medicine.

BCA acknowledged the importance of the debate about the right of patients to die with dignity as a co-sponsor of the state-wide Conference on Physician Aid in Dying. On a less controversial topic, BCA endorsed bills limiting the ability of insurance companies and public hospitals to require women to have outpatient mastectomies.

And we continued our efforts to assure easy access to information about all cancer clinical trials by monitoring implementation of the "one stop shopping" law that Breast Cancer Action initiated at the federal level in 1996.



A CLEAR VOICE ORGANIZING THE COMMUNITY

Breast Cancer Action is a membership-based organization that values the involvement of grassroots activists throughout the country and around the world in working to end the breast cancer epidemic. Our grassroots task forces—Media Response, Community Outreach, Audre Lorde Action Brigade, Legislative Action, and Treatment Issues—work with our members and staff to advance the goals of the organization.

Our principal community organizing event in 1998 was our Second Annual Town Meeting for Breast Cancer Activists, featuring authors Dorothy Allison and June Jordan. More than 400 people gathered to hear Allison describe the revolutionary act of believing that she had a right to question how her own body was treated and to celebrate the fact that things are changing because, as she put it, “we are all of us warriors.” June Jordan captured the essence of activism, describing it as the situation in which “you do something rather than nothing. . . . You do whatever you can, you reach beyond yourself.”

BCA also worked with other community-based organizations in San Francisco to co-sponsor the first Bayview/Hunters Point Breast Cancer Town Hall, which brought information and a message of community, hope, and activism to an underserved population for which breast cancer has been for far too long a silent and private tragedy.

Breast Cancer Action’s community organizing is built on the idea that everybody can do something that matters about the breast cancer epidemic. Responding to the call, hundreds of people were involved with BCA Task Forces in 1998, working on a variety of grassroots activities.

MEDIA RESPONSE

From California to Iowa to New York to Kentucky, members of BCA’s Media Response Task Force wrote letters to the editor and opinion pieces responding 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 addressed topics including premature reports of the benefits of raloxifene for reducing breast cancer risk, stories implicitly depicting breast cancer as a white woman’s disease, and media silence on European trials that showed no benefit for healthy women taking tamoxifen to reduce the risk of breast cancer. Task Force members also participated as active audience members on television programs addressing breast cancer issues.



LEGISLATIVE ACTION

Guided by BCA policy positions and sample letters, Legislative Action Task Force members communicated their views to both California and federal representatives on a number of issues. Subjects addressed included a school pesticide right-to-know law, genetic-based discrimination in employment, treatment funding for poor women screened for breast cancer through state and federal programs, allocation of funds from the breast cancer stamp, and the pesticide methyl bromide.

TREATMENT ISSUES

Members of BCA's Treatment Issues Task Force attended the 1998 San Antonio Breast Cancer Symposium and actively participated in addressing some of the critical issues in the conventional treatment of breast cancer that were discussed at the conference. In a smaller forum, Task Force members posed hard questions to researchers who made presentations at the 1998 University of California Breast Cancer Symposium. This Task Force also addressed issues of access to care at San Francisco's public hospital.

COMMUNITY OUTREACH

Throughout 1998, Community Outreach Task Force members showed up at events throughout the San Francisco Bay Area to provide information about breast cancer from BCA's perspective. Supported by trainings and materials developed by BCA, our members gave thousands of people a new perspective on breast cancer and what can be done about it.

AUDRE LORDE ACTION BRIGADE

Audre Lorde was a social activist and writer who envisioned an "army of one-breasted women" descending on Congress to demand change. Though she died of breast cancer at age 58 in 1992, Lorde's spirit lives on in the women and men who take to the streets as part of BCA's Action Brigade. In 1998, the Brigade's activities included handing out fliers about Breast Cancer Industry Month at freeway on-ramps, demonstrating against waste incinerators in a poor neighborhood of Oakland, California, protesting pharmaceutical company sponsorship of the San Francisco March Against Cancer, and participating in the annual Cancer Industry Tour of San Francisco.



BCA SUPPORTERS

Breast Cancer Action's work is inspired by the millions of people whose lives have been forever changed by breast cancer, and made possible by the astounding generosity of individuals and institutions who believe, as we do, that fundamental changes in society are necessary to end the breast cancer epidemic.

In addition to the supporters listed below, BCA gratefully acknowledges the financial assistance of donors at all levels, who together provide more than half of the organization's annual budget.

\$25,000 AND UP

The *California* Endowment

\$10,000 – \$24,999

The Gaea Foundation • The Wallace Alexander Gerbode Foundation • Wells Fargo

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FINANCIAL STATEMENT

INCOME AND EXPENSES, 1998

INCOME

Individual Contributions	\$ 161,153	45.8 %
Foundation Grants	115,853	32.9 %
In-kind Gifts	7,881	2.2 %
Events & Other Revenue	67,142	19.1 %
TOTAL INCOME	\$ 352,029	100. %

EXPENSES

Program	\$ 273,501	77.2 %
General Support	42,807	12.1 %
Fundraising	38,092	10.7 %
TOTAL EXPENSES	\$ 354,400	100. %

BALANCE SHEET, DECEMBER 31, 1998

ASSETS

Current Assets

Cash and Cash Equivalents	\$ 129,044
Certificates of Deposit	10,200
Grants Receivable	66,080
Prepaid Expenses	3,209
TOTAL CURRENT ASSETS	\$ 208,533
Fixed assets, net of accumulated depreciation	\$ 15,057
TOTAL ASSETS	\$ 223,590

LIABILITIES AND NET ASSETS

Current Liabilities

Accounts payable and accrued expenses	\$ 4,892
TOTAL CURRENT LIABILITIES	\$ 4,892

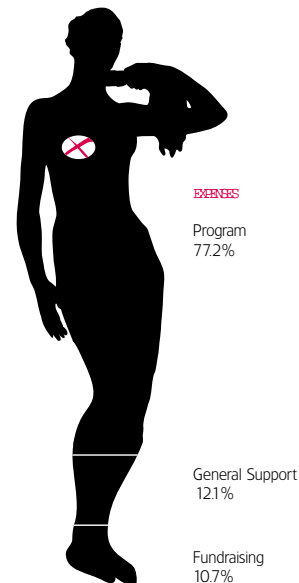
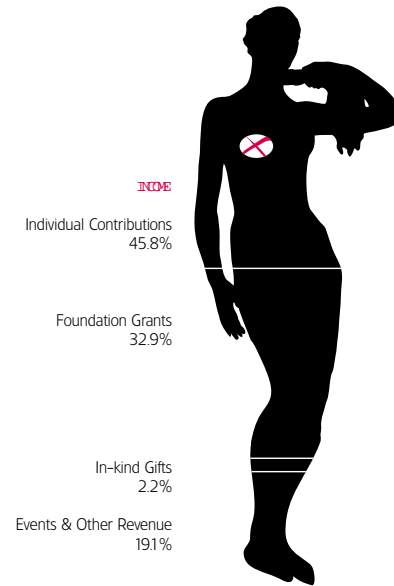
Net Assets

Unrestricted

Undesignated	\$ 10,023
3-month cash reserve (board designated)	89,000
Board designated program (media and public education campaigns)	58,000
Total Unrestricted Net Assets	\$ 157,023

Temporarily Restricted Net Assets	\$ 61,675
TOTAL NET ASSETS	\$ 218,698

TOTAL LIABILITIES AND NET ASSETS	\$ 223,590
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