

**BREAST
CANCER
ACTION**



**AGENT
FOR
CHANGE**

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BREAST CANCER ACTION

55 New Montgomery Street, San Francisco, CA 94105

Phone: 415-243-9301, Fax: 415-243-3996

e-mail: bcaction@hooked.net

Website: <http://www-med.stanford.edu/bca>

MISSION STATEMENT

The mission of Breast Cancer Action is to serve as a catalyst
for the prevention and cure of breast cancer.

Our goals are: to make the eradication of breast cancer a national priority
through education and advocacy; to promote and refocus research into the causes,
prevention, treatment and cure of breast cancer;
and to empower women and men to participate fully in decisions
relating to breast cancer.

On the Cover: The Prayer Flag ©Breast Cancer Action, designed to call the world's attention to
the breast cancer epidemic,
to create lasting hope for those who have been
diagnosed, and to establish a memorial for those who have died.
For information on the Prayer Flag Project, contact the Breast Cancer Action office.

Annual Report: Design: Roberta Lampert; Editing: Kathleen Wilkinson;
Photography: Beverly Tharp (page 2); Jim Piper (page 3); Dolores Bermak (page 8)
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Not quite a decade ago, several pioneering women in a breast cancer support group in San Francisco decided it was time to **get organized**. Frustrated and angry with the systematic lack of **information** about the **causes of and treatment for** breast cancer,

Elenore Pred, Susan Claymon, Belle Shayer and others who shared their passion and concern

wanted the public to know

the truth about breast cancer

and sought to galvanize the political support necessary to stop this epidemic.

To that end, in the summer of 1990, they formed

Breast Cancer Action (BCA).

Breast cancer

is not

BCA began with monthly meetings to **inform** members about breast cancer —

what was known

and what wasn't.

They circulated a photocopied handout,

which has become BCA's bimonthly newsletter, now nationally recognized as

a leading publication in breast cancer advocacy.

an individual woman's

personal tragedy;

it is a tragedy

for all women

and together

we have the power

to change things."

— the late Elenore Pred,

co-founder, Breast Cancer Action

Sharing the truth with women who have the disease was only part of the battle, however. The women who founded BCA

wanted to **make their voices heard**:

they **tracked** legislation related to breast cancer

and **testified** before legislative bodies to

inform public representatives about the **realities of the disease**.

They **scrutinized the media**, following

press reports on breast cancer issues

and demanding that the truth be told.

They **took to the streets**, marching for

compassionate access to experimental therapies and for

more public focus on this terrible epidemic.

Today, BCA is still led by women living with breast cancer

and works hard to **continue the legacy** of its founders.

Over the past seven years, it has become a

prominent national grassroots organization with

over 2,200 members and supporters across the country.

BCA is proud of its achievements as an **agent for change**.

As this report shows, BCA's work helped mark 1996 as the

beginning of a new era

in nationwide breast cancer advocacy.

WE CALL THIS ANNUAL REPORT "BREAST CANCER ACTION: AGENT FOR CHANGE," because that is precisely what we do day in and day out in our quest to serve as a catalyst for the prevention and eradication of breast cancer. These pages contain our reflections on a year in which public awareness of breast cancer reached new heights, individual involvement in grassroots efforts continued to climb and federal funding for breast cancer increased.

What brought about these changes? Not so many years ago, breast cancer was a secret that forced women and men to seek their own ways through the terrifying maze of diagnosis and treatment. But when courageous survivors shone the light on themselves and started telling their stories, an amazing thing began to happen: people realized that we and our loved ones didn't have to live alone in fear or die alone in silence.

Breast Cancer Action is the living legacy of that strength and determination. In this our seventh year, we honor each other and ourselves by building upon the anger, fear, pain and sadness of breast cancer as we solidify BCA into an organization that will be fighting for as long as it takes to bring an end to this devastating disease.

We believe, along with our brothers and sisters in the AIDS and civil rights movements, that silence indeed equals death. Our individual and collective voices demand answers: we must find the causes, understand prevention and discover a cure for an epidemic that knows no boundaries. We take your cries seriously, for they are our own.

Karen L. Strauss

Karen L. Strauss
President, Board of Directors





1996 WILL LIKELY BE NOTED IN HISTORY AS THE YEAR IN WHICH BREAST CANCER FIRST HIT THE BIG time. From weekly press stories about the latest development in diagnosis or treatment to politicians using the concern about breast cancer as part of their election strategy, the breast cancer epidemic was never far from the public eye. The extraordinary level of coverage — featuring breast cancer research funding, new genetic tests for hereditary susceptibility, the link between estrogen and breast cancer, outpatient mastectomies — culminated with *The New York Times Magazine* cover story on breast cancer charities in late 1996.

This increased visibility is a testament to the effectiveness of breast cancer activists all over the country. Policymakers sought our views on issues that affect everyone, particularly genetic testing and environmental links to breast cancer. Under the moniker “consumer,” we gained more access to the meetings and conferences where decisions that affect our lives are made — in the halls of Congress and the conference rooms of the National Cancer Institute. And, thanks to efforts coordinated by the National Breast Cancer Coalition (of which BCA is a member), federal funding for breast cancer research exceeded \$300 million last year.

We can congratulate ourselves on successfully garnering this unprecedented public attention, but we must also remember to look at what it has meant in real terms. The breast cancer incidence rate continues to climb while the death rate has hardly budged. There is still no cure for breast cancer and no way to prevent the disease.

The challenge that faces us now is to work together to generate effective treatments and true prevention. We must continue to see our own interests clearly and to “tell the truth to power.” The more we speak out about the realities of breast cancer, the more quickly change will happen.

Barbara A. Brenner

Barbara A. Brenner
Executive Director

MAKING
THE
CASE
FOR
CHANGE:
Education
and
Advocacy

DURING 1996, BREAST CANCER ACTION'S EDUCATION AND ADVOCACY EFFORTS took many forms. But whether educating politicians, talking to the press, publishing a newsletter, sponsoring a community forum or responding to requests for information, BCA's goals were always the same: to empower people to deal with the myriad issues raised by a breast cancer diagnosis and to refocus research priorities toward true prevention and cure.

DIRECT ADVOCACY

Though a young organization, BCA is often called upon at both national and state levels to participate in decision-making about key breast cancer issues. BCA also provides unsolicited views when necessary to make sure that the voices of women living with breast cancer are heard. Highlights of BCA's advocacy efforts during 1996 include:

Making Her2/neu experimental therapy available to more women by teaming up with others to pressure manufacturer Genentech into creating a compassionate access program; meeting with representatives of pharmaceutical companies to ensure that patient concerns about side effects of new treatments were addressed.

Chairing the Consumer Advisory Group for the Hereditary Susceptibility Working Group of the National Action Plan on Breast Cancer; presenting consumer concerns to the National Cancer Institute Genetics Working Group and the National Action Plan conference on the State of the Science of Hereditary Susceptibility.

Serving on peer review panels for the federal Department of Defense Breast Cancer Research Program.

Urging Health and Human Services Secretary Donna Shalala to allocate funds for breast cancer research to agencies that focus on environmental links.

Participating in the California Breast Cancer Research Program stakeholders meeting to develop priorities for future funding and providing input on program design and priorities by serving as consumer monitors for the program.

Planning and participating in the San Francisco Breast Cancer Summit, focusing on issues of research, epidemiology and access to screening and treatment.

Presenting informational talks on such topics as patient needs and rights for the University of California Symposium on Clinical Trials Design, clinical trials accessibility for the National Action Plan on Breast Cancer and environmental links to breast cancer for Marin Breast Cancer Watch.

Making presentations on the risks of genetic testing to the Stanford Working Group on Genetic Testing for Breast Cancer Susceptibility, at the World Conference on Bioethics and at the National Leadership Conference on Medicine in the Era of Genetics.



MEDIA PRESENCE

BCA's knowledge about breast cancer issues makes the organization an important resource for breast cancer-related media stories. BCA representatives were featured in a number of published articles throughout 1996, and the media sought BCA's comments and expertise on the following topics last year: breast cancer genetic testing, compassionate access to experimental therapies, environmental links to breast cancer, radiation and breast cancer, diet and breast cancer, mammograms for young women, the breast cancer stamp, breast cancer activism, drive-through mastectomies, breast cancer statistics and realities, patenting of genes, breast cancer incidence in San Francisco's Bayview/Hunter's Point and Bay Area breast cancer treatment resources.

The range of media venues through which BCA's views were presented was similarly broad, including national television and print media, international radio and television and San Francisco Bay Area television, radio and print media.

The agency also participated in press conferences on a variety of issues, including medical standards of care for breast cancer patients, the use of pesticides in San Francisco parks and Bay Area breast cancer rates.

BCA developed its own media messages for radio and television with the pro-bono help of the advertising firm of Saatchi & Saatchi. San Francisco radio station KPIX-FM aired the public service announcements throughout the year without charge.

LEGISLATIVE EFFORTS

BCA's support is sought regularly by state and federal legislators for bills related to breast cancer detection, treatment or prevention. BCA endorses proposed legislation that is consistent with its goals and works to see that necessary legislation is introduced. BCA also regularly informs its membership about pending bills of interest. In activity that foreshadowed a dramatic increase in legislative interest, BCA supported the following bills in 1996:

In the U.S. Congress: "One-stop shopping" for information on cancer clinical trials (not passed, but reintroduced in 1997). This bill was formulated in response to congressional testimony given by BCA.

In the California State Legislature: Expanded access to experimental treatment for terminally ill patients (AB 1663, Friedman — passed and signed into law). Required use of chlorine-free paper (not passed). Study presence of dioxin in feminine hygiene products (not passed).

THE BCA NEWSLETTER

The BCA Newsletter unflinchingly covers the science and politics of the disease, including the links between the environment and breast cancer, the cancer industry's profiteering on detection and treatment methods and political battles over critical information about research and new therapies. Stories about new developments in treatment — with unbiased information about risks and benefits — have always taken center stage.

Breast Cancer Gene Doesn't Cause Disease

Exploiting Breast Cancer

To the Editor:

Second only to the tragedy of breast cancer itself is the travesty of the business world making a buck off of it ("National Breast Cancer Awareness Month Has Inspired Extensive Corporate Advertising, Advertising column, Oct 3)

Selling products like pink-ribbon

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BCA worked effectively

to further public awareness

of breast cancer issues

and realities.

Public education is the key to

increased support for research

and development of

prevention and a cure.

FURY OVER BREAST CAN

Thanks to outreach efforts that began taking shape in 1996, distribution of the newsletter increased 30 percent during the year, and BCA established newsletter exchanges to share critical information with other organizations working on issues of women's health and environmental health. The newsletter now goes to 2,500 individuals and institutions throughout the country and beyond. Institutional subscribers range from libraries to legislators.

We are becoming

a nation of very sick people,

thanks to chemicals,

radiation,

environmental racism,

poverty, and

corporate greed.

This must change . . .

As we make the link

with each other and with the

grassroots movement that is

spreading across

the country, we become

a powerful force for change.

Breast cancer can serve as

a wedge to open the minds

of the public to the links between

health and the environment.

Nancy Evans

BCA Board Member

Addressing the San Francisco

Breast Cancer Summit

November 9, 1996

Highlights of the topics covered during 1996 include:

Mammography: challenging the "early detection" myth

Tamoxifen: telling the truth about a wonder drug

Managed Care: navigating the strange new world of health care

Patient Rights: Family Medical Leave Act

Treatments: what's working and what's not, prognostic guides for ductal carcinoma in situ (DCIS)

Diagnostics: blood tests, ultrasound

Genetics and Breast Cancer: treatment research, testing dangers

Federal Initiatives: FDA drug approval, pesticide law

Environmental Hazards: xenoestrogens, pesticides

BCA COMMUNITY FORUMS

BCA's commitment to community education is demonstrated in the Community Forum Series. The four 1996 forums drew more than 400 participants to hear information and exchange ideas on the following topics:

Tamoxifen Update with Dr. Michael DeGregorio

The Genetics of Breast Cancer with Dr. Mary Claire King

Death and Dying with author Christina Middlebrook

The Politics of Breast Cancer with three breast cancer activists

INFORMATION AND REFERRAL

During 1996, BCA received and filled thousands of requests for information on matters ranging from appropriate diagnostic procedures, to compassionate access for treatment, to the effectiveness of non-allopathic treatments. These requests came from women recently diagnosed, from their partners and loved ones, from students making their first foray into the world of breast cancer, from doctors and from the general public.

BCA BOOKSTORE

BCA makes available for sale books on breast cancer topics that members and others will find useful as they confront the many decisions related to diagnosis, treatment and prevention. Many of the titles are not widely available from mainstream sources.

COALITION EFFORTS

By working with others who share BCA's views and approaches to critical issues, the agency is far more effective than it could ever be working alone. During 1996, BCA tackled a variety of issues in conjunction with other organizations:

Genetic testing for breast cancer: American Cancer Society, National Action Plan on Breast Cancer

Industrial development in Bayview/Hunter's Point: Southeast Alliance for Environmental Justice, Toxic Links Coalition

Opposition to patenting of human genes: multiple organizations

Opposition to development of a low-level radioactive waste dump at Ward Valley, California: Greenpeace, Toxic Links Coalition and many other organizations

Health and environmental justice: National Coalition on Health and Environmental Justice

Kaiser Hospital recommendations for prophylactic mastectomies for women with genetic alterations related to breast cancer: National Action Plan on Breast Cancer, California Alliance of Breast Cancer Organizations

GROWING TO MEET THE CHALLENGES AHEAD

When the
United States Postal Service
introduced a
breast cancer awareness stamp,
BCA designed an alternative.
BCA's

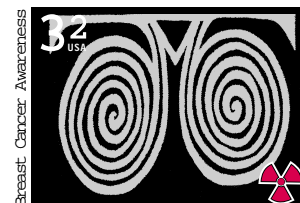
WITH BREAST CANCER FINALLY CAPTURING the national attention that it deserves, Breast Cancer Action readied itself to continue to meet the demands of an unrelenting epidemic. Recognizing the need to build the foundation that would keep BCA in the forefront of breast cancer issues for as long as necessary, the Board of Directors took bold steps to secure the organization's infrastructure. For the first time, BCA has a full time Executive Director whose personal experience with breast cancer, legal training, and organizing experience give the agency a responsible and articulate voice in a sound administrator.

New board members have brought both diversity and new energy to the organization, and plans are underway to increase BCA's presence and activities. Work with an organizational development consultant has helped the agency define and prepare to meet its structural needs. Through task forces established in 1996, BCA has created a volunteer-driven fundraising program that will assure that the agency can fulfill its promise to be a leading force in breast cancer advocacy. A \$50,000 grant the Richard and Rhoda Goldman Fund during 1996 reflects an enormous vote of confidence in the importance of BCA's work. As BCA prepared to launch its 1997 Men's Campaign Against Breast Cancer, the agency received a tremendous boost from James C. Hormel, who awarded a \$25,000 challenge grant to BCA for the Campaign.

BCA has put into place new programs to strengthen its impact over the coming years. Thanks to volunteer efforts, information about the organization is now accessible on the Internet through its web site. Through the creation of a Scientific Advisory Board, BCA will institutionalize its ability to be well-informed on current issues in the science of breast cancer. Dr. Joycelyn Elders will keynote our first Town Meeting for Breast Cancer Activists in November 1997, where people will be given the opportunity to become more involved in the critical work of "telling the truth to power" to end the breast cancer epidemic.

Working with other breast cancer advocates has taught us much. Now that breast cancer is on the top of the public agenda, BCA faces the challenge of making sure that it stays there until the epidemic is ended.

The future is now, and we are prepared to meet the challenge.



stamp design affirms those
who have confronted breast cancer.

It uses two coils —
symbols of the lunar cycle
found on breast plates of
ancient female warriors.



During 1996, Breast Cancer Action received generous support from the following private foundations and corporations:

- Richard & Rhoda Goldman Fund
- The Gaea Foundation
- The Charles and Helen Schwab Family Foundation
- The Van Loben Sels Foundation
- McKesson Employees Community Fund
- Citibank

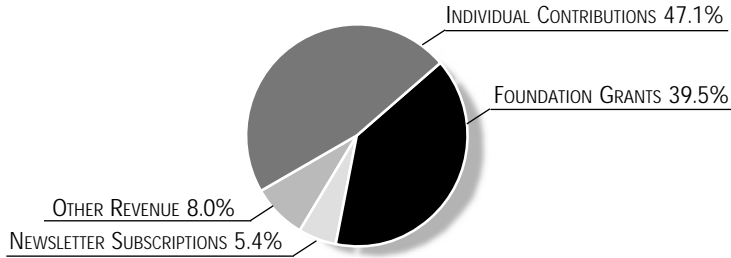
BCA's work is funded in great part by generous individuals across the country, all of whom have been touched in some way by breast cancer. Many of these women and men struggle each day to survive. Without express permission to print their names, we gratefully acknowledge them here as a group. BCA deeply appreciates their support and honors their efforts by its work.



*Standing left to right: Karen Strauss, President; Elaine Elinson; Rachel Morello-Frosch, Secretary; Barbara A. Brenner, Executive Director; Kyra Subbotin; Jane Sprague Zones; Lindsay Wakeman, Office Coordinator
Seated left to right: Ada Renée Williams; Belle Shayer, Treasurer; Susan Claymon, Vice President; Nancy Evans, Vice President
Not pictured: Jackie Hicks; Lucy Sherak; Alicia Madocks, Bookkeeper*

INCOME

Individual Contributions	\$ 76,788	47.1%
Foundation Grants	64,447	39.5%
Newsletter Subscriptions	8,845	5.4%
Other Revenue	13,093	8.0%
TOTAL	\$ 163,173	100.0%



EXPENSES

Program	\$ 113,606	74.1%
General Operations	25,570	16.7%
Fundraising	14,241	9.3%
TOTAL	\$ 153,417	100.0%

NET INCOME \$ 9,756

BALANCE SHEET DECEMBER 31, 1996

ASSETS

Current Assets

Cash	\$ 54,246
Pledges receivable	1,250
Grants receivable	2,500
Prepaid expenses	1,749
TOTAL CURRENT ASSETS	59,745

Fixed assets net of accumulated depreciation 9,308

TOTAL ASSETS \$69,053

LIABILITIES AND NET ASSETS

Current Liabilities

Accounts payable and accrued expenses	\$ 2,947
TOTAL CURRENT LIABILITIES	2,947

Net Assets

Unrestricted	63,606
Temporarily Restricted	2,500
TOTAL NET ASSETS	66,106

TOTAL LIABILITIES AND NET ASSETS \$69,053

A copy of Breast Cancer Action's 1996 audited financial statement is available on request.