

Celebrating Activism



THE POWER OF ACTIVISTS

15th Anniversary

ANNUAL REPORT 2005

mission statement

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



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EVERY MAJOR CHANGE IN THE WORLD OF breast cancer has happened because people came together and demanded it. The women who founded Breast Cancer Action in 1990 met in a breast cancer support group and decided to move from illness to activism. Joining forces, they created a grassroots organization based on their belief in the power of community and their understanding of the disease's political, economic, and social context.

When BCA was formed, breast cancer was rarely discussed in public. The organization's founders helped spur great change in the world of breast cancer in the early 1990s—change that transformed the disease from a private medical crisis to a national health emergency.

Breast Cancer Action's founders believed that providing information to anyone who needed it, and educating the public, the media, and policy makers, were essential in moving toward a world in which everyone had access to the treatment they needed, in which the treatments were less toxic and more effective, and in which the environmental triggers of breast cancer were understood and eradicated.

Fifteen years later, BCA is a national leader in breast cancer education and advocacy, with more than 16,000 members across the United States and around the globe. The organization is propelled forward by activists and volunteers in communities everywhere. Through education, outreach, community-based organizing, and public policy advocacy, BCA's staff and volunteers work to increase public access to vital information and resources about breast cancer, and help people do something—besides worry—about the disease.

BCA exists because far too many people have been affected by this disease. As we celebrated 15 years of activism in 2005, the organization renewed its commitment to continue educating, agitating, and organizing for as long as it takes. We know that the work we do is made possible by the efforts of activists and everyday people who care deeply about breast cancer and those it affects. What these people have accomplished and continue to accomplish is an inspiration.

Carrying the Voices of People Affected by Breast Cancer

BCA's mission is to carry the voices of people affected by breast cancer to inspire and compel the changes necessary to end the epidemic. Because we remain close to our grass roots—the people affected by breast cancer and those at risk for the disease—we hear about their needs, as well as their challenges, victories, and experiences.

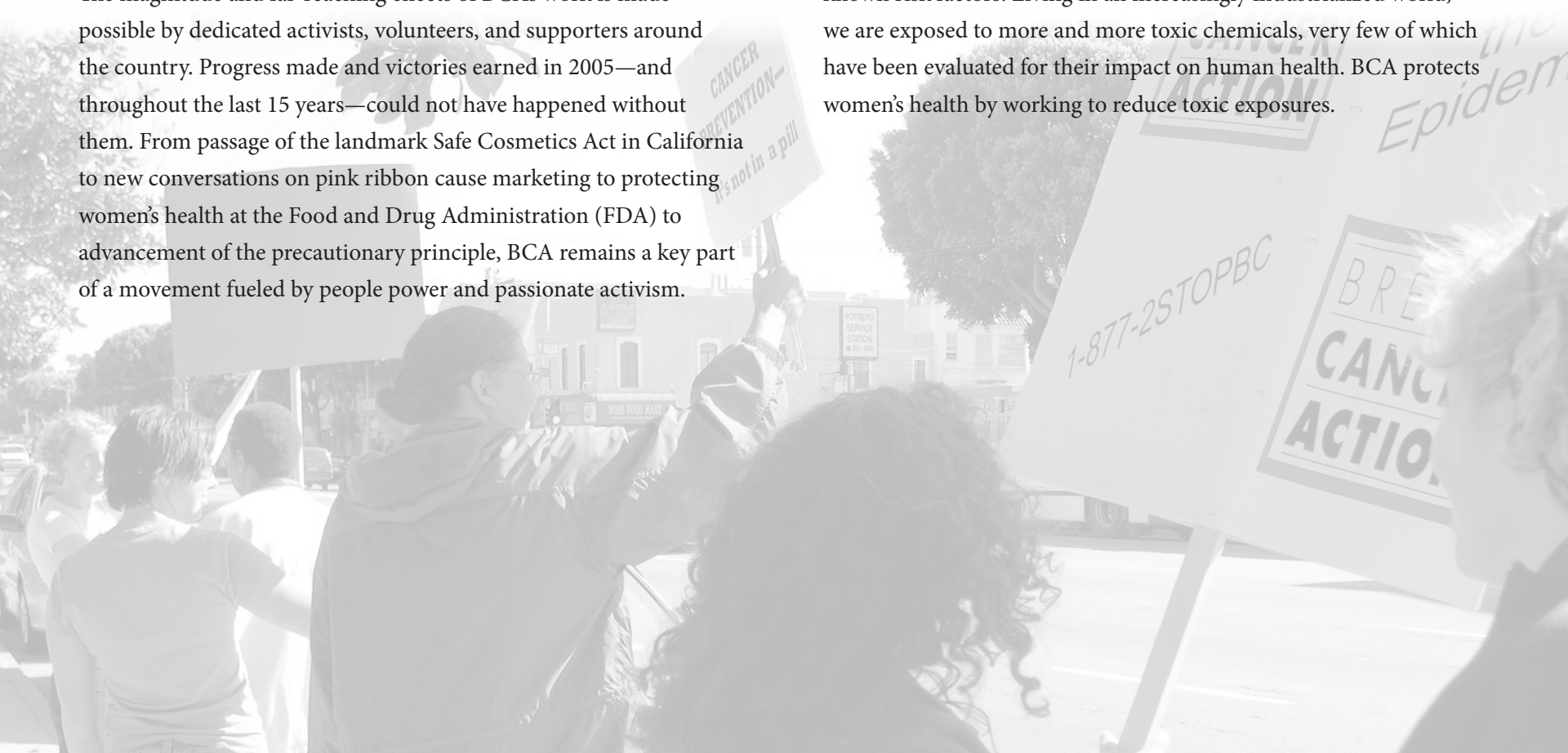
Grassroots Organizing

The magnitude and far-reaching effects of BCA's work is made possible by dedicated activists, volunteers, and supporters around the country. Progress made and victories earned in 2005—and throughout the last 15 years—could not have happened without them. From passage of the landmark Safe Cosmetics Act in California to new conversations on pink ribbon cause marketing to protecting women's health at the Food and Drug Administration (FDA) to advancement of the precautionary principle, BCA remains a key part of a movement fueled by people power and passionate activism.

Stopping Cancer Where It Starts

A key aspect of BCA's work is advocating for a shift of focus to stopping cancer where it starts. While many of the messages the general public hears regarding breast cancer are about screening or pills for “prevention,” BCA knows that the only way to truly prevent breast cancer is to stop it before it starts. When the majority of women with breast cancer have none of the known risk factors, and as incidence rates continue to rise, we must address the impact of environmental factors.

More than half of breast cancers cannot be explained by any of the known risk factors. Living in an increasingly industrialized world, we are exposed to more and more toxic chemicals, very few of which have been evaluated for their impact on human health. BCA protects women's health by working to reduce toxic exposures.



Victory for Safer Cosmetics

Passage of the landmark California Safe Cosmetics Act, SB 484, was made possible by the work of activists around the state who supported the efforts of BCA and the bill's other cosponsors. The law, which takes effect in 2007, will require cosmetics manufacturers to disclose to California's Department of Health Services any ingredients that are known by the state to cause cancer or birth defects. We mobilized concerned consumers throughout California to tell their legislators and the governor that we deserve personal care products that are free of toxic ingredients.

BCA and our allies garnered media coverage, in addition to activist support, including featured coverage on KQED radio—San Francisco's NPR station—and editorials in favor of SB 484 in the *San Francisco Chronicle* and the *San Jose Mercury News*. BCA spokespersons also talked with several Spanish-language media outlets, concentrating on California's Central Valley and the Los Angeles area. BCA's lobbyist in Sacramento bolstered these efforts.

By the end of the legislative session, the multibillion-dollar cosmetics industry—which named the legislation's defeat as its top priority for the year—was no match for dedicated everyday people speaking out for change. The victory attracted national attention, including a mention in a blog by Katrina vanden Huevel, editor of *The Nation*.



Secondhand Smoke and Breast Cancer

Secondhand smoke is considered an environmental toxin. In early 2005 California's Air Resources Board released a report concluding that exposure to secondhand smoke is linked with an increased incidence of breast cancer, especially in young women. This is particularly true when the exposure happens in early childhood. The topic was featured in the *BCA Newsletter* and received coverage on the CBS Evening News and in *USA Today*.

Advancing the Precautionary Principle

Much of BCA's work on safe cosmetics—and reducing exposure to toxic chemicals—is based on the precautionary principle, which says, “First, do no harm.” This is a “better safe than sorry” approach to public health. Rather than waiting years or decades to find that a particular chemical is safe, consumers should not be exposed to chemicals that might be harmful. The burden should be on manufacturers to prove safety, rather than on consumers to prove harm.

BCA's work with the Bay Area Working Group on the Precautionary Principle saw a local government victory in 2005, with passage of a precautionary purchasing ordinance in San Francisco. Member groups continued working with the city of Berkeley on passage of a similar ordinance there.

BCA participates in the Environmental Health Legislative Working Group and serves on the steering committee of Californians for Pesticide Reform. For the second year in a row, BCA attended the National Institute for Environmental Health Science's conference on breast cancer and the environment, asking hard questions about how the agency's research is structured and what it might tell us about environmental links to breast cancer.



Deconstructing Herceptin Hype

Throughout the year, information on the potential benefits of Herceptin for early-stage breast cancer was slowly trickled out to the public. BCA worked hard to get the real story—and the real numbers—behind the press releases and oral presentations that came months before the October release of the full data on this powerful drug.

Herceptin is a biotech therapy beneficial to a subset of women with breast cancer whose disease may be more aggressive because their tumors overexpress a protein called HER2/neu. The drug is currently approved by the FDA only for women with metastatic breast cancer. While press reports touted relative benefit numbers (the effects on the whole group of patients studied), BCA reported the absolute numbers (those that are most meaningful for an individual woman with the

disease). BCA also took on the National Cancer Institute's (NCI) claims that the drug “cures” breast cancer and pointed out that the drug's nearly \$50,000-per-year price tag means that many women won't be able to afford its benefits.

Collecting Drug Side Effect Information

A class of drugs called aromatase inhibitors are the latest thing in hormonal therapy for breast cancer in postmenopausal women. These drugs are increasingly favored over tamoxifen. BCA has expressed concerns over the past several years that short- and long-term side effects of the drugs are largely unknown. As we began to hear from women that they were experiencing unanticipated or otherwise problematic effects, BCA decided to systematically collect side effect information.

In summer 2005, BCA launched a comprehensive online survey to collect side effect information about aromatase inhibitors. Nearly 500 women had taken the survey by the end of the year. The survey is ongoing, and initial results will be analyzed and released as they become available.

Countering Pills for Prevention

Long critical of the use of pills for the “prevention” of breast cancer in healthy women, BCA faced a new challenge in 2005 with the announcement of a clinical trial of exemestane—an aromatase inhibitor marketed as Aromasin—in healthy women. BCA encouraged women not to enroll in the trial, just as we did with the announcement of similar trials of tamoxifen and raloxifene in healthy women. As BCA said to top print, television, and radio reporters, the risk-benefit ratio of a powerful drug is far different for healthy women than it is for women with breast cancer. Concerned that treating risk as disease will lead to disease substitution rather than prevention, BCA countered messages from the National Cancer Institute and others by calling for a focus on the causes of breast cancer rather than risk reduction through powerful pills.

FDA Advocacy

BCA continued its years-long coalition efforts to keep silicone breast implants from being reapproved for use by the general public. BCA submitted testimony to the FDA demanding assurances of safety—which has yet to be proven—before the devices are reintroduced to the public. When the FDA ignored our testimony, we sent letters to Congress and authored an op-ed in the *San Francisco Chronicle*.

NCI director Andrew von Eschenbach was named interim director of the FDA, prompting BCA to warn that juggling the two positions deprived both agencies of much-needed full attention. BCA also spoke out about the dangers of von Eschenbach's promotion of fast-track drug approval and his evident failure to understand that the FDA's job is to assure that drugs are both safe and effective before they are marketed.

Think Before You Pink

BCA encouraged activists to continue asking hard questions of companies with pink ribbon marketing campaigns in the fourth year of Think Before You Pink. This campaign is BCA's answer to the messages around "Breast Cancer Awareness Month" in October that suggest that activism should take the form of buying things. Referring to October instead as "Breast Cancer Industry Month," BCA continues to change the conversation from awareness to meaningful action.

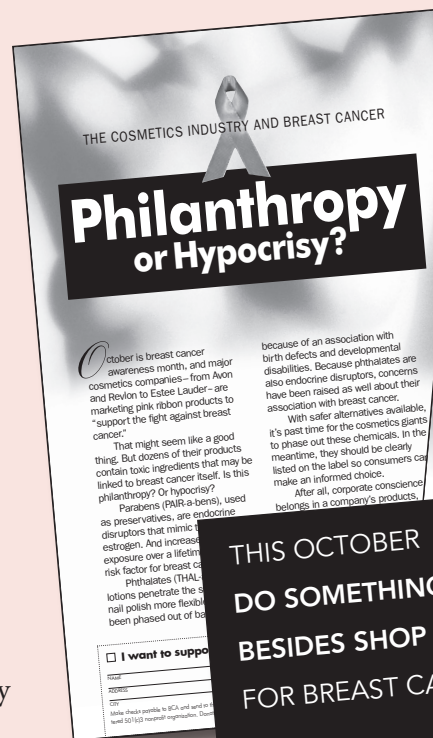
Think Before You Pink in 2005 included an Internet Flash movie that raised questions about how much money is being raised and how much companies spend on marketing their pink ribbon products. The e-movie culminated in a call to action, telling corporations to put people before profits. People sent e-mails directly from BCA's web site to 20 companies from the "Parade of Pink" list asking six key questions, including: "How much money from each product sold actually goes toward breast cancer?" "How much did you spend marketing the products?" and "What is your company doing to assure that its products are not contributing to the breast cancer epidemic?" Other organizations have followed suit, calling for consumers to ask similar questions. The campaign also featured an expanded "Parade of Pink"—an online sampling of more than 50 pink ribbon marketing campaigns.

Response to the campaign has grown each year, with visits to www.thinkbeforeyoupink.org totaling over 40,000 by the end of October and a thousand e-mails sent to companies with pink ribbon marketing campaigns. Throughout fall 2005, Think Before You Pink messages were featured twice in the *New York Times*, other top newspapers around the country, and in several high-profile blogs. Questions raised by the campaign led PRwatch.org to issue a "Falsies Award" to pink ribbon marketing.

think before



you pink



Information Is Essential

Women should have access to all the information necessary to make decisions on breast cancer treatment, diagnosis, and screening. Additionally, information is an essential precursor to action. BCA has always been committed to providing accurate, reliable, and honest information about breast cancer. By providing information, BCA both enables people to make informed decisions for themselves and supports their activism.

In 2005 we mailed the *BCA Newsletter* to an ever-expanding list of more than 15,000 individuals and institutions. We published medical news, coverage of controversial subjects, analyses of new science, book reviews, and inspiring activist profiles. Our bimonthly newsletter, provided free to anyone who requests it, is highly regarded in the world of women's health.

BCA's Spanish-language newsletter, *Saber Es Poder* ("Knowledge Is Power"), focuses on issues of specific concern to Spanish-speaking communities. We distributed more than 1,600 copies of each issue in 2005 to people around the U.S. and internationally.

We also function as a resource through our acclaimed web sites and toll-free number (877/2-STOP-BC). In 2005 we responded to thousands of phone calls and e-mails. BCA's web site (www.bcaction.org), which received an average of 32,000 visits per month in 2005, serves as a comprehensive source of information for individuals around the globe.

BCA's status as an independent watchdog organization and information provider is bolstered by our strict corporate contributions policy, which prohibits the organization from taking money from companies that profit from or contribute to breast cancer incidence, including



pharmaceutical companies and chemical manufacturers. The information BCA provides and the policy positions it takes are never influenced by corporate interests. BCA was the first national breast cancer organization to adopt this policy, one that has been followed by a number of local and regional organizations around the country.

1990

BCA's first meeting is held in founder Elenore Pred's living room. "We are meeting to organize Breast Cancer Action," the flyer announced. "Our goals are education and political action to prevent a further rise in breast cancer."

The first BCA Newsletter is published.

In 2005 the newsletter is sent to more than 15,000 subscribers.

1991

BCA founders Elenore Pred, Susan Claymon, Belle Shayer, Linda Reyes, and other breast cancer activists meet with the director of the National Cancer Institute (NCI) to demand that the agency address the breast cancer epidemic.

Following the death of Elenore Pred, Susan Claymon becomes the first breast cancer activist to address the President's Cancer Panel in Washington, D.C.

By 2005 BCA has a regular presence at annual cancer conferences, including the San Antonio Breast Cancer Symposium.

1992

BCA study groups meet throughout the year to evaluate treatment options, environmental links to breast cancer, alternative therapies, legislative developments, and breast cancer biology.

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

1993

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

In 2005 BCA continues to serve on the California Breast Cancer Research Council, helping to guide the program to fund research in new ways.

BCA participates in a national signature gathering campaign to call for a strategy to end the breast cancer epidemic—2.6 million signatures are presented to President Clinton. BCA plays a key role in the federal Breast Cancer Summit called in response.

1994

BCA testifies before the FDA 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.

By 2005 BCA has regularly submitted testimony to the FDA on drugs and devices related to breast cancer.

BCA brings noted worldwide scientists together for a session entitled Breast Cancer: The Environmental Connection at the annual meeting of the American Association for the Advancement of Science.

1995

BCA becomes a founding member of the Toxic Links Coalition, making the link between women, health, and the environment. The coalition organizes the first annual Cancer Industry Tour of headquarters of companies contributing to the cancer epidemic.

BCA calls for the drug tamoxifen to be added to the list of substances known to the State of California to cause cancer. Despite the objections of Zeneca (the drug's manufacturer) and then-Governor Pete Wilson, BCA's argument prevails in 1996.

1996

In testimony before a U.S. Senate committee, BCA calls for "one-stop shopping" for information on cancer clinical trials, modeled on centralized AIDS trial information.

Congress passes such a law in 1999.

BCA leads the call for guarantees of privacy and insurance and employment protection before genetic testing for breast cancer is routinely used. BCA, the National Action Plan on Breast Cancer, and others work to ensure that consumer interests are protected in the marketing of genetic testing.

BCA works with San Francisco Mayor Willie Brown to plan and present the city's first Breast Cancer Summit.

1997

BCA holds its First Town Meeting for Breast Cancer Activists, featuring former U.S. Surgeon General Dr. Joycelyn Elders, and launching BCA's activist Task Forces focused on media, legislation, treatment, community outreach, and street activism.

Citing the absence of evidence that routine mammography screening reduces breast cancer deaths for women aged 40 to 49—and noting the risks of mammography screening, including radiation exposure and the risk of false positives and false negatives—BCA publicly opposes the call by the NCI, the ACS, and others for routine screening among women in this age group.

1998

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

BCA places a full-page ad in the *New York Times* addressing the corporate role in Breast Cancer Awareness/ Industry Month and the resulting lack of focus on environmental links to breast cancer.

1999

BCA launches its Spanish-language information project, *Saber Es Poder* (Knowledge is Power), and publishes the first edition of its Spanish language newsletter.

During a visit by the NCI director to San Francisco, BCA's Audre Lorde Action Brigade stages a street demonstration calling for federally funded research into the environmental links to breast cancer.

2000

BCA leads the call to guarantee that poor and uninsured women screened for breast cancer at state expense receive prompt access to quality treatment at state expense.

In 2005 BCA joined with other women's health advocates to call for universal access to health care in San Francisco as a model for the state and nation.

BCA launches the Think Twice Before You Walk campaign, urging people to ask how much money raised through fundraising events goes to breast cancer.

2001

BCA conducts its first membership survey, giving members an opportunity to communicate who they are and how the organization can represent and serve them more effectively.

The first monthly BCA e-alert is sent.

By 2005, the e-alert list has grown to over 6,000 subscribers.

2002

BCA launches its Think Before You Pink Campaign. The campaign urges consumers to ask critical questions before supporting pink ribbon marketing campaigns.

BCA plays a key role in convening the first International Summit on Breast Cancer and the Environment, funded by the Centers for Disease Control.

BCA's web site wins the People's Choice Webby Award for best health web site.

BCA jointly releases the first edition of the report "State of the Evidence: What is the Connection Between the Environment and Breast Cancer?"

2003

BCA convenes advocacy meetings at the San Antonio Breast Cancer Symposium—the largest annual scientific meeting on breast cancer in the U.S.

BCA presents testimony to the FDA opposing attempts to reintroduce silicone breast implants, citing numerous safety concerns.

2004

BCA launches the Breast Cancer Puzzle Project, calling for a coordinated approach to research, focused on key unanswered questions that remain about the disease.

Led by BCA, the Follow the Money Alliance puts a resolution before Avon shareholders calling for the removal of harmful chemicals from its products.

In 2005 the BCA-led Follow The Money Alliance for Accountability in Breast Cancer includes other health organizations and socially responsible investment companies calling for transparency in corporate breast cancer funding.

2005

BCA launches an online aromatase inhibitor survey to collect information on the side effects of this new form of breast cancer treatment.

BCA's coalition work around chemicals in cosmetics is advanced with the passage of SB 484, the California Safe Cosmetics Act.

BCA works closely with the cities of San Francisco and Berkeley to ensure timely and effective implementation of ordinances adopting the precautionary principle of public health as a matter of policy.

BCA celebrated its 15th anniversary.

ACKNOWLEDGEMENTS

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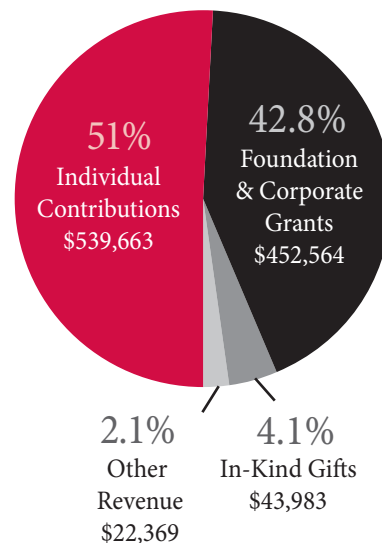
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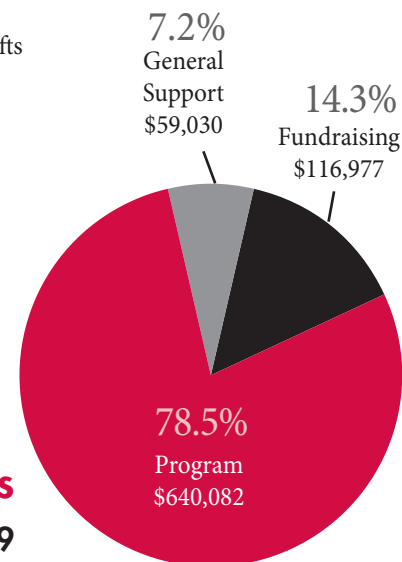
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Total: \$816,089



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