



GRASSROOTS ADVOCACY MAKES A DIFFERENCE!

California Breast Cancer Organizations (CABCO)

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ABSTRACT

Since 1990 California Breast Cancer Organizations (CABCO) has worked with the California legislature in an effort to fulfill its mission: the eradication of breast cancer through education and advocacy. CABCO is a grassroots organization comprised of member organizations and individual members representing thousands who are affected by breast cancer. CABCO, working with other groups, has been a moving force in obtaining passage of significant legislation in the State of California and, as a board member organization of the National Breast Cancer Coalition (NBCC), in Washington, DC.

California has been a leader in breast cancer screening programs, research, treatment and cancer clinical trials as a result of legislation advocated for by CABCO, its members and other groups in the state. The California Breast Cancer Act, passed in 1993, marked the first CABCO success in advocacy. This groundbreaking legislation levied a two cent tax on cigarettes:

50% for a breast cancer screening program for women over 40 (BCEDP)

45% for breast cancer research. An innovative CA Breast Cancer Research Program (CBCRP) was created to fund CA scientists and organizations doing research to alleviate the burden of breast cancer in the state

5% for the California Cancer Registry. The CA Cancer Registry initiated the CA Teachers Study, a prospective study following a cohort of 133,000 teachers.

To further fund breast cancer research CABCO worked in 1994 to create a "check-off" on state income tax forms that allows a tax-deductible donation to the CBCRP. In 2007 this provision was renewed for an additional five years.

With the establishment of these programs there were provisions for advocates to play a role in their execution. Advocates serve on the governing bodies and on the advisory task forces for each of these programs.

As women were being diagnosed with breast cancer using the screening program with no provision for treatment, CABCO worked to obtain funding from the California Endowment to provide a treatment program for those diagnosed through the BCEDP and a federal program that had been created in the Centers for Disease Control and Prevention. In 2000, when this funding expired, CABCO advocates succeeded in obtaining state budgetary funding to continue the treatment program. At the same time CABCO members were working with NBCC to obtain passage of a federal treatment program. In 2001 CABCO worked with the California Governor to have the state budget include funding to "opt in" to the federal treatment program. This funding continues to be included in the state budget.

As another way to support research CABCO initiated a clinical trials bill to promote cancer patient participation in clinical trials. This was successful in 2001. Insurers are now required to cover ordinary patient costs for those in clinical trials. A study by the University of California, Davis in 2003 validated that this legislation has had a positive effect on clinical trial participation by cancer patients.

Grassroots advocacy is effective! Dedicated, passionate CABCO advocates in California, working with the legislature and other organizations, have changed the face of breast cancer in California. Screening and treatment have been provided and creative research is being conducted. Trained, educated advocates with a passion to eradicate breast cancer make a difference.

ADVOCACY RESULTS

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| 1992 DEPARTMENT OF DEFENSE BREAST CANCER RESEARCH PROGRAM CREATED | 2001 CALIFORNIA "OPTS IN" TO BREAST AND CERVICAL CANCER TREATMENT ACT OF 2000 |
| 1993 BREAST CANCER ACT OF 1993: 2-CENT CIGARETTE TAX. CREATION OF SCREENING PROGRAM, RESEARCH PROGRAM AND FUNDING FOR CANCER REGISTRY | 2002 TAX CHECK-OFF LINE EXTENDED TO 2008 |
| 1993 TAX CHECK-OFF LINE ON PERSONAL INCOME TAXES FOR BREAST CANCER RESEARCH PROGRAM | 2002 CONTINUED FUNDING IN GOVERNOR'S BUDGET FOR TREATMENT |
| 1994 TREATMENT FUNDING OBTAINED | 2003 STUDY FINDS THAT CLINICAL TRIAL LEGISLATION PASSED IN 2001 HAS EFFECTIVELY REDUCED BARRIER TO CLINICAL TRIAL PARTICIPATION |
| 1997 RENEWAL OF TAX CHECK-OFF LINE TO 2003 | 2004 BREAST AND CERVICAL CANCER TREATMENT PROGRAM ELIGIBILITY DETERMINATION RETAINED IN DEPARTMENT OF HEALTH SERVICES |
| 1999 TREATMENT "BRIDGE" FUNDING OBTAINED | 2007 TAX CHECK-OFF LINE EXTENDED TO 2013 |
| 2000 CONGRESS PASSES BREAST AND CERVICAL CANCER TREATMENT ACT | |
| 2001 CLINICAL TRIALS BILL PASSED | |

Department of Defense Breast Cancer Research Program

Advocates from the National Breast Cancer Coalition worked to establish the Department of Defense Breast Cancer Research Program. In 1992 it began with appropriation of \$25,000,000. Each year since grassroots advocates led by the NBCC have influenced public policy and obtained a congressional appropriation for innovative, peer-reviewed breast cancer research.

Total Congressional funding appropriated for this program is \$3.45 billion from inception through fiscal year 2008.

Clinical Trials

CABCO initiated legislation to provide that ordinary patient costs incurred by patients, who participate in high quality clinical trials, must be paid by insurers.

1999 CABCO presented model legislation to Assemblyman Howard Wayne

2000 In this legislative session, the bill did not succeed, but Governor Davis promised he would support clinical trial legislation in 2001.

2001 Senator Jackie Speier reintroduced the bill. It was one of three bills sponsored by the governor in the 2001 legislative session. Clinical Trials bill passed. CABCO was present at the signing.

2003 UC Davis study found the bill was accomplishing its goal of increasing participation in clinical trials.

Breast Cancer Treatment

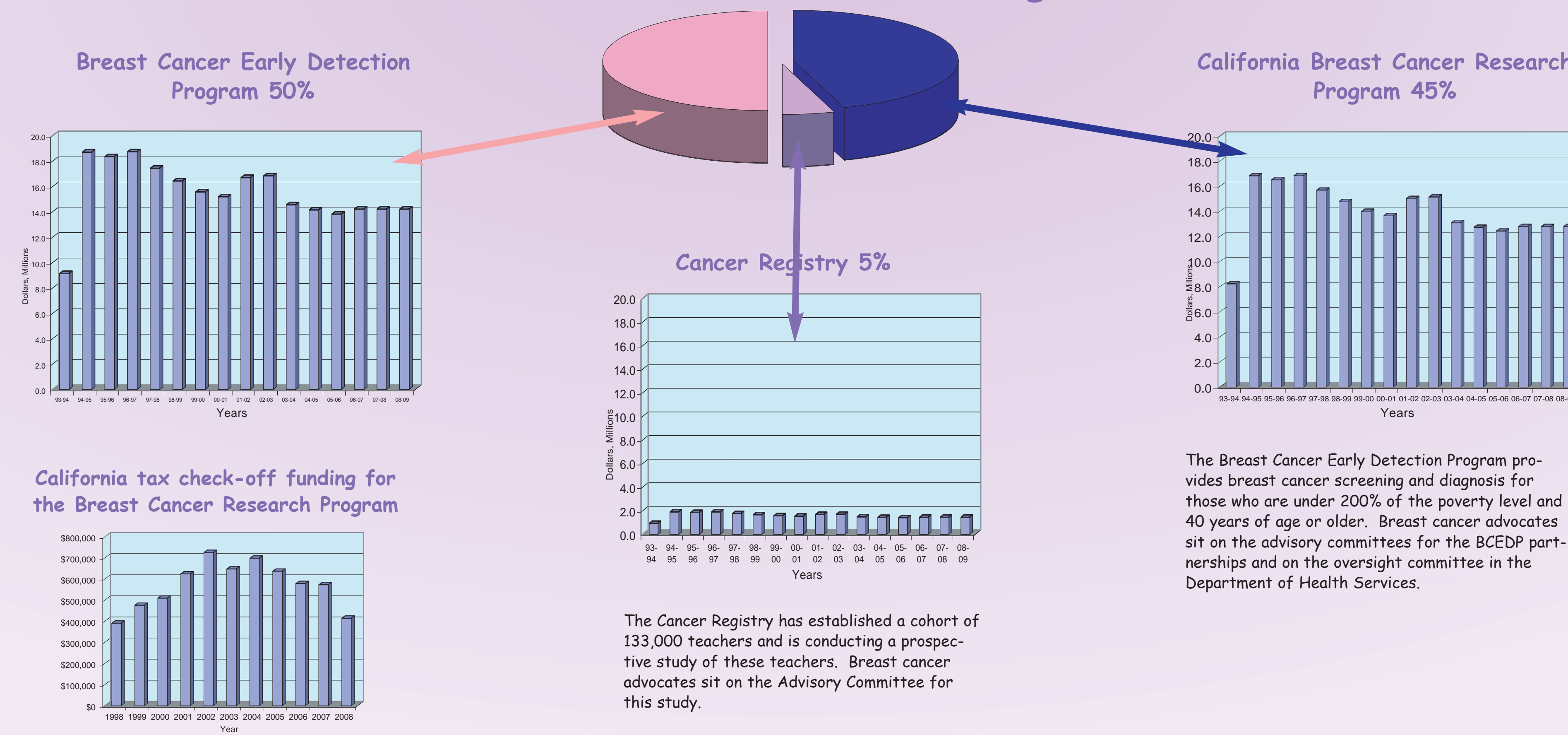
California has two treatment programs. The Breast and Cervical Cancer Treatment Act provides complete MediCal coverage for the length of the breast cancer treatment. The California Treatment Program provides coverage for 18 months of treatment for breast cancer only. The California program does not have citizenship as a requirement for eligibility. Advocates sit on the advisory committee for the California Treatment Program.

CABCO advocates worked with NBCC to obtain passage of the Breast and Cervical Cancer Treatment Act of 2000.

PROGRAMS INITIATED BY CABCO AND OTHER ADVOCATES: EFFECT ON RESEARCH AND ACCESS TO QUALITY HEALTHCARE

- Department of Defense Breast Cancer Research Program**
 - CABCO advocates work with the National Breast Cancer Coalition to obtain Congressional funding for the innovative breast cancer research program that NBCC originated.
 - Advocates serve at all levels of the program: Integration Panel to determine program priorities and final funding and scientific peer review panels.
- California Breast Cancer Research Program.**
 - California advocates sit on the council that determines areas to be funded and allocates funding to provide balanced research portfolio that funds breast cancer research in California.
 - Advocates from outside California have equal voice on scientific review panels that evaluate the research proposals.
- Every Woman Counts (BCEDP) Screening Program**
 - Advocates have a seat on the council that oversees the statewide screening program that is run under the Dept. of Health Services.
- Breast Cancer Treatment Program**
 - Originally this program was funded by funding that advocates obtained from the California Endowment and the California Healthcare Foundation. Advocates had a seat on the council that oversees this program.
 - CABCO worked with NBCC to win passage of the federal Breast and Cervical Cancer Treatment Act of 2000 and to have California "opt-in" to the program.
- Cancer Registry (California Teachers Study)**
 - Advocates have seats on the External Advisory Task Force for this prospective cohort study of 133,000 teachers.
- Clinical Trials**
 - Advocates, using a model from NBCC, initiated the legislation and worked to educate the governor and legislature on clinical trials to obtain passage of this important bill that makes a difference in patient participation in clinical trials, providing evidence based medicine.

The Breast Cancer Fund: 2-Cent Cigarette Tax



SUMMARY

Funding Obtained for California Breast Cancer Programs 1993-2008	
Treatment	\$73,200,000
Cigarette Tax	
Screening	\$247,900,000
Research	\$223,100,000
Cancer Registry	\$12,800,000
Research- Tax Check-off	\$6,975,000
TOTAL	\$575,975,000

CONCLUSION

Put a face on breast cancer with dedicated, passionate, educated survivors and legislators will listen! Grassroots advocacy has been very effective providing funding for programs to provide breast cancer screening, diagnosis and treatment, creating and providing funding for breast cancer research programs and initiating Clinical Trials legislation that helps reduce the barriers for patient participation in clinical trials.

