



The Breast Cancer Family Registry Celebrates 20 Years

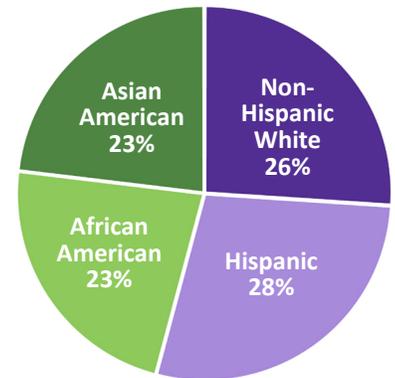
Twenty years ago, in the fall of 1995, the National Cancer Institute (NCI) established the Breast Cancer Family Registry at six international centers in the U.S., Canada, and Australia to study the genetic origins of breast cancer.

Through a series of funding cycles from NCI, highlighted in the 20-year timeline below, the Breast Cancer Family Registry has enrolled and followed over 11,000 multigenerational families with more than 4,000 enrolled through the Northern California site at the Cancer Prevention Institute of California (CPIC).

The Breast Cancer Family Registry is a unique resource for interdisciplinary studies of breast cancer risk factors for women, especially those at increased familial and genetic risk. It includes large numbers of families with early-onset breast cancer, high-risk families with multiple affected family members, as well as families with triple negative breast cancer, a type of breast cancer that is particularly difficult to treat. Among the participants enrolled in Northern California, there is a substantial representation of racial/ethnic minority families (accounting for 75 percent of California families enrolled).

The information gained through the Breast Cancer Family Registry has contributed many new insights into the genetics of breast cancer through the discovery of new genetic factors, the role of potentially modifiable lifestyle factors in women at increased breast cancer risk and how they interact with genetic factors, and behavioral issues that are relevant for the clinical setting.

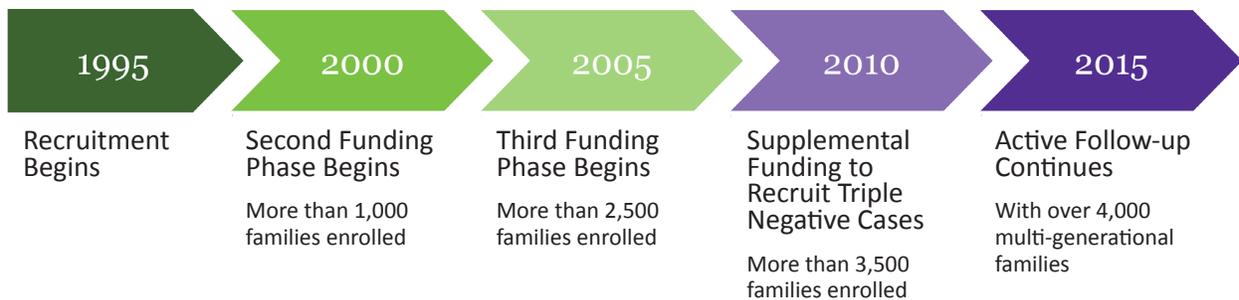
Thank you for your continued support and participation in this very important study! Please see back page for testimonials from members of some of our longest participating families.



**California
Breast Cancer
Family Registry:
1995-2015**
Racial/Ethnic Distribution of
Families in Northern California

California Breast Cancer Family Registry: 1995-2015

20 Years of Studying the Genetic Origins of Breast Cancer in Northern California



Dr. Esther M. John Named CPIC Director of Research

Esther M. John Ph.D., M.S.P.H., the Principal Investigator of the Northern California site of the Breast Cancer Family Registry, was recently appointed Director of Research for the Cancer Prevention Institute of California (CPIC). In addition to her responsibilities at CPIC, Dr. John holds a Consulting Professor position in the Department of Health Research and Policy at the Stanford University School of Medicine, and is one of the Co-leaders of the Population Sciences Program at the Stanford Cancer Institute.

Dr. John's research focuses on identifying factors that contribute to racial/ethnic disparities in breast and prostate cancer development and prognosis. She collaborates with many research groups and leads the Bay Area site of several multicenter studies, including the Breast Cancer Family Registry, the WECARE (Women's Environment Cancer and Radiation Epidemiology) study, and the LEGACY (Lessons in Epidemiology and Genetics of Adult Cancer from Youth) Girls Study.



New Family Registry Follow-Up Survey Launched

Over the years, we have followed Family Registry participants, either annually for brief updates, or 10 and 15 years into the study for more comprehensive updates. We recently launched a new mail-in survey that will allow us to gain a deeper understanding of the factors associated with breast cancer development and prognosis, survivorship issues among women diagnosed with breast cancer, communication about breast cancer risk in the family, and genetic testing. Information from this recent survey will help us translate our findings into community prevention programs, clinical practice, and health policy.

The new survey will be mailed to participants through 2017. So far, more than 1,000 surveys have been completed and returned. If you receive this important survey in your mail, please complete it and send it back to us. We truly appreciate your time and effort!

Have you recently moved?
If you are planning to move, or recently changed your address, please let us know by calling our toll-free number (1-888-441-2643) or e-mailing us at frbc@cpic.org.

Visit us online to read more about the Family Registry and to view our published research findings
www.frbc.cpic.org

For latest study news and developments from all five Breast Cancer Family Registry sites please visit
www.bcfamilyregistry.org



Please meet the current team of Family Registry coordinators and telephone interviewers! They are committed to helping you complete the new mail-in follow-up survey and answering any questions you may have. Top row (left to right): Zinnia Loya, Shanika Anderson, Marianne Dellner and Judy Goldstein. Bottom Row: Elaine Ramos, Jolyn Smith, Susie Huey-Lee, Mariam Aejaz and Jenny Nguyen.

Why I Participate

Pam - "When I was a participant in a clinical trial in 2000, I remember talking to a nurse who told me I was doing this so our daughters won't have to in the future. I am more than happy to participate in any way that helps people in the future – be it my daughter or a stranger. To this day, I believe the only good thing from a cancer diagnosis is helping others who come after – sharing yours experiences, listening, and just being there."



Pam, Janice and Jackie (left to right) are long time registry participants.

Janice - "I joined the Family Registry because I wanted to do anything that would help women - all women regardless of race or ethnicity. Research gains knowledge and knowledge is the power we need to fight this disease."

Jackie - "My hope is that I give as much information as I can so that it will make a difference not just for breast cancer patients, but all cancer patients, as I believe all cancers are related."