



The Northern California Family Registry for Breast Cancer Newsletter

Where we've been...

In 1995, the National Cancer Institute (NCI) funded the Breast Cancer Family Registry (BCFR) at six medical research institutions from the U.S., Canada and Australia in order to answer many important questions about genetic factors affecting breast cancer susceptibility and modification by environmental and lifestyle factors. Over the last ten years, the Northern California Family Registry, along with its five international partner sites, have contributed to the creation of a unique and powerful resource that can address many of the unanswered questions on the causes and prevention of breast cancer.

"BCFR's guiding aim is to answer important questions about the causes of breast and ovarian cancer that can be translated into development of better ways to prevent and treat these diseases. This crucial work would not be possible without the help of you and your family."
 ~ Daniela Seminara Ph.D., M.P.H.
 Program Officer NCI

Where we are right now...

More than 2800 women and men with breast cancer and over 4000 of their family members are participating in the Northern California Family Registry. They have completed questionnaires and donated much appreciated blood samples. We thank you all for saying YES to this important project. The information and biological samples you have contributed are serving to benefit a large number of breast cancer studies worldwide. It is dedication from people like you who are making the Family Registry a research success.

White, non-Hispanic	872
Hispanic	568
African-American	541
Chinese	393
Filipino	282
Japanese	102
Other Asian	100
Total	2,858

Where we're going...

With continued funding from NCI, the next phase of recruitment will focus on the enrollment of African-American and Hispanic families, with the goal of enrolling 800 new families between 2006 and 2010. Large numbers of minority families are needed to address many unresolved questions surrounding the racial/ethnic differences in breast cancer. One very important feature of the Northern California Family Registry is the racial diversity of the San Francisco Bay Area population; 70% of all non-white families enrolled in the BCFR come from the Bay Area.

By participating in our Family Registry you are a critical part of the bigger picture. We thank you for making the biggest donation to research beyond dollars –

YOURSELF! 😊

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Volunteer Opportunity

We would like to form a Family Registry Participants' Advisory Group to provide us with participant perspectives regarding a variety of research and study issues. Your input will help inform the decisions we make. We anticipate that participation will involve occasional communication by phone and email as issues arise, and one or two in-person meetings per year. Let us know if you are interested by email to

frbc@nccc.org or
call 1-510-608-5025.



Update on LEGACY Pilot Study

Last year, we reported to you that the Family Registry was interested in the possibility of expanding the participating families to include members under the age of 18 years. Including children and adolescents in our research would offer the rare opportunity to study the importance of early life events and exposures in the development of breast cancer, a time period when prevention strategies may be particularly effective.

To learn more about the possibility of doing this, we began the Legacy Pilot Study in the fall of 2005 and completed telephone interviews with 20 women who have daughters between the ages of 5 and 15 years. Similar studies were done with Family Registry participants in Utah and Ontario, Canada. We tried to learn about the attitudes, interests, and concerns of Family Registry participants as regards enrolling daughters under age 18 years into the Family Registry.

We are very grateful to the women who took the time to speak with Dr. Caren Frost on this topic. The interviews focused on a number of themes, including communication about cancer in the family, parental concerns about research in children, recommendations from parents regarding future study participation of their daughters, the roles of parents and daughters during participation, and the ages at which parents would be comfortable with enrolling daughters.

Lessons in Epidemiology and Genetics of Adult Cancers from Youth



Thus far we have learned that parents felt it was important to identify the appropriate maturity level of daughters to participate. Parents expressed a belief that their daughters' participation would be both altruistic (helping their own family members and other families) and beneficial to daughters themselves to learn about their own health.

We received some very concrete recommendations for structuring a study that would include children. Parents thought that the study should take full advantage of available information and obtain as much information as possible from adult family members and family physicians to decrease the daughters' awareness of cancer in their family. The study should ensure that activities are

flexible in scheduling, and that study staff involved with the daughters' participation are female to minimize daughters' discomfort.

The idea of involving children and adolescents in the Family Registry is both intriguing and challenging. Our next steps are to continue analyzing data from the pilot interviews and to come up with solutions for incorporating the important suggestions and concerns that have been raised during the process. If you have any further input to add regarding the Legacy project, please email frbc@nccc.org or call 1-510-608-5025.



If you are a Family Registry participant

we invite you to mail or e-mail your story in 500 words or less. Tell us how breast cancer has affected your life, good or bad, and share with us why you're committed to being part of the Northern California Family Registry. Your story may be printed in our next newsletter or on the website that we are developing.

Mail to Northern California Family Registry, c/o Enid Satariano, 2201 Walnut Avenue, Suite 300, Fremont, CA 94538-9903 or email frbc@nccc.org.

The Northern California Family Registry newsletter needs a name! Send us your suggestions by email to frbc@nccc.org or call 1-510-608-5025.

Genetic Studies of Breast Density

Last year the National Cancer Institute funded a new study among participating sisters at the Ontario, Australia, and Northern California Family Registries to learn more about the appearance of breast tissue on a mammogram.

The type of tissue seen in a mammogram varies between people and is partially inherited. Research using mammograms may give us important information about the future risk of breast cancer. In this study we



hope to identify the genes that influence the type of tissue that women have in their breasts. Such information will help us better understand the causes of breast cancer, and ultimately

help the development of new prevention strategies and more effective treatments.

To do this research we need to borrow mammograms from sisters who are Family Registry participants. You may be invited to participate in this study if you and your sisters indicated on your original questionnaire that you have had one or more mammograms in the past. If you are contacted, we hope you will help us out with this important new study. ☺

Blood Matters

A big THANK-YOU to all of our participants who have already donated a blood sample to the Family Registry. If you are among those who have not yet agreed to donate blood or have been reluctant to have your family members participate in the Family Registry, we need your help. Each and every blood sample collected is valuable, and our goal is to obtain samples from all participating families. Please help us reach this goal.

Simply stated, a blood sample is one of the most important pieces of information collected from participants. Using the blood sample along with the questionnaire data is the only way the Family Registry can answer important questions about the role of genetics and lifestyle factors in the development of breast cancer. Many of these studies require large numbers of samples and more than one blood sample from each family. Your cooperation makes a difference!

Our experienced phlebotomists can schedule a blood donation anywhere in the greater San Francisco Bay Area at times that fit your schedule. If you live farther away, or prefer to have your health care provider draw your blood, we can help you make the arrangements. Please email us at frbc@nccc.org or call our toll-free number 1-888-441-2643.

Two new bi-lingual Spanish speaking interviewers began working with the Family Registry in the last six months.

Inga Gonzalez is a telephone interviewer who does



many of the brief telephone interviews that determine eligibility for the Family Registry. She also helps out with the annual follow-up interviews. She has twins, Michael and Amber who are just about to turn 3, and keep her very busy! She especially enjoys taking them to the beach.

Ritela Zendejas-Brewer is an interviewer-phlebotomist.



She brings many years of experience as a medical and nutrition assistant as well as a phlebotomist. She enjoys outdoor activities such as river rafting and camping and spending as much time as she can with her seven grandchildren!

Research Update

Scientists working with the Breast Cancer Family Registry have published over 100 reports in scientific journals that analyzed data and biospecimens provided by Family Registry participants. Two of these reports are reviewed here.

Breast cancer risk in women carrying mutations in BRCA1 or BRCA2 genes. Women who have mutations (abnormal changes) in these genes have a higher risk of developing breast cancer than women without such mutations. It is therefore important to find out how mutation carriers can decrease their risk of developing breast cancer. Past studies have shown that drinking 2 or more glasses of alcohol

per day increases the risk of developing breast cancer. This Family Registry study found that alcohol did not further increase the risk of breast cancer in mutation carriers. Work is under way to assess the effects of oral contraceptive use, smoking, and radiation exposure on breast cancer risk in mutation carriers.

Cancer in relatives of breast patients. First-degree relatives of patients with breast cancer have an increased risk of developing breast cancer. Risk is higher in relatives of patients diagnosed at a young age than in relatives of patients diagnosed at a later age. We recently studied breast cancer patients without mutations in *BRCA1* or *BRCA2* genes, and

examined the occurrence of cancer in their relatives. We found that breast cancer risk was higher in relatives of patients with early-onset breast cancer than in relatives of patients diagnosed at a later age. This finding suggests that mutations in genes other than *BRCA1* or *BRCA2* are important. The Family Registry resources will be critical in identifying such genes. 😊

For a list of publications and research findings already made possible by your participation, please visit
<http://epi.grants.cancer.gov/CFR/>

If you have questions regarding the Family Registry please call
1-510-608-5025 or
email frbc@nccc.org

WEBSITES

www.nc-frbc.org

Scheduled to launch in late 2006.

www.nccc.org

Is the site for the Northern California Cancer Center, our parent organization. Provides information and links to studies, local events and research findings. Click "Cancer Research" and "Family Registry for Breast Cancer."

<http://epi.grants.cancer.gov/CFR/>

Is the official website for the Breast Cancer Family Registries, where you can find more information about the California Family Registry and the other participating registries.

www.cancer.gov

Is the official website for the National Cancer Institute

www.breastcancer.org

Is a nonprofit organization dedicated to providing complete and up-to-date information about breast cancer.

www.breastcancer.net

Is the place to go to subscribe to daily or weekly e-mail summaries of breast cancer related research and treatment news being published worldwide. You can try it free for two weeks.

<https://chess.chsra.wisc.edu/espanol>

Is a new online resource for spanish-speaking breast cancer patients and their families with links to other educational materials in Spanish for Latinas created by trusted sources such as the NCI, the American Cancer Society and the Susan G. Komen Breast Cancer Foundation.

BOOKS

The Northern California Cancer Center has a number of books on working through and living with cancer. The publications are free for the first copy and \$3 for each additional copy. Download publications from www.nccc.org/education/education_edpubs.html



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