



The Northern California Family Registry for Breast Cancer Newsletter

Summer 2010

A Message from our Research Director...



Dr. Esther John

Thank you again for your continued participation in the Northern California Family Registry for Breast Cancer. It has been an amazing journey ever since we started this research program in 1995! You, along with more than 8,300 women and men are active participants in our Family Registry. Across the 6 registries in the US, Canada,

and Australia, over 35,000 individuals from over 14,000 breast cancer families have given their time to be part of the Breast Cancer Family Registry.

You and your family members have contributed valuable interview data and biospecimens, completed yearly follow-up interviews, and participated in various add-on studies addressing new research questions. All of the information has been consolidated into one large resource that is recognized world-wide as a unique and most valuable resource for addressing many unanswered questions on the causes and prevention of breast cancer.

Over 170 research teams have used this outstanding research resource, and over 250 scientific publications have been generated (<http://epi.grants.cancer.gov/CFR>). This important work would not be possible without your continued participation and your dedication to the Family Registry. We are very grateful to you and your family for supporting our research efforts focused on breast cancer prevention.

NEW NAME. NEW LOOK.
The Northern California Cancer Center is now the
CANCER PREVENTION INSTITUTE OF CALIFORNIA
Please visit the new website www.cpic.org
NEW Family Registry website www.frbc.cpic.org

LEGACY (*Lessons in Epidemiology and Genetics of Adult Cancer from Youth*)

What if we knew how to prevent breast cancer from occurring! What if we knew what young girls could do to prevent breast cancer later in life. Several years ago, we told you about an exciting new research idea that involves studying girls from families with breast cancer and comparing them to girls from families without breast cancer. We first conducted a series of telephone interviews with families who are part of the Family Registry and learned that they were generally supportive of their daughters participating in research studies (see page 2, under *Published Research*).

In 2009, we launched LEGACY, a study that has never been done before. LEGACY invites girls between the ages of 6 and 13 years, some of whom have family members with breast cancer and others who don't have a family history. Along with their mother, the girls participate in interviews, complete measurements of height and weight, and provide biospecimens. We then follow the girls as they grow up, and contact them and their mothers every six months in order to keep track of changes in activities, nutrition, growth, and development. So far, our interviewers, Sonja and Debbie (see page 3, under *Staff Highlights*), have enrolled 86 girls and their mothers who live in the San Francisco Bay area, and 53 girls and their mothers have already completed one or two

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Published Research from the Northern California Family Registry

Many of you have asked us to keep you up-to-date on research findings from the Family Registry. Over the years, the data and biospecimens you and other Northern California Family Registry participants contributed have led to more than 45 scientific publications. Three recent publications are highlighted below:

A qualitative study evaluating parental attitudes towards the creation of a female youth cohort (LEGACY) in the Breast Cancer Family Registry. Glendon et al., *Psychooncology* 2010.

We recently completed a telephone survey with parents and asked about their willingness to have their daughters participate in a research study called LEGACY (Lessons in Epidemiology and Genetics of Adult Cancer from Youth). The LEGACY study will examine lifestyle, environmental, and genetic factors that affect pubertal development in young girls from families with breast cancer, and for comparison, in young girls from families without breast cancer. We completed telephone interviews with 85 parents who had daughters between the ages of 6 and 17 years. A special thank-you to the participants from the San Francisco Bay Area! We found that 92% of parents were willing to have their daughters enroll in a study like LEGACY. Although there were some concerns about their daughters' possible anxiety, overall, parents were very supportive of this study.

Given the positive response from parents and receipt of some start-up funding, we have launched the LEGACY

study and enrolled 86 girls and their mothers (see page 1). We are hoping to expand this study into a much larger project, pending funding from the National Cancer Institute.

Performance of prediction models for BRCA mutation carriage in three racial/ethnic groups: Findings from the Northern California Breast Cancer Family Registry. Kurian et al., *Cancer Epidemiology Biomarkers & Prevention* 2009.

Patients who are diagnosed with breast cancer or ovarian cancer at a young age often wish to know if they inherited a mutation in *BRCA1* or *BRCA2*, two known breast cancer genes. Because genetic testing for these genes is very expensive, prediction models are used in clinics to help identify individuals who are likely to have an inherited mutation in *BRCA1* or *BRCA2* and



therefore may choose to be tested. Several prediction models have been developed in non-Hispanic white women, but it is not known whether these models work equally well in other populations who may have different types and different frequencies of mutations in these genes. We tested two of these

models in the Northern California Family Registry and found that the models would work better with some refinements specific for Hispanic and African American women. As we learn more about the occurrence of *BRCA1* and *BRCA2* mutations in these populations, we will be able to develop better prediction models that are specific for Hispanics and African Americans.

Family history of breast cancer and all-cause mortality after breast cancer diagnosis in the Breast Cancer Family Registry. Chang et al., *Breast Cancer Research & Treatment* 2009.

It has long been known that having a first or second degree relative with breast cancer increases a woman's chances of getting breast cancer herself. However, it is not clear whether a positive family history affects survival after breast cancer is diagnosed. This study looked at a sample of 4,153 breast cancer patients and found that five-year survival was equally high, regardless of family history. These results suggest that family history of breast cancer does not adversely affect patient outcomes.

For a more complete listing of publications please visit <http://epi.grants.cancer.gov/CFR/> If you would like to receive a copy of any of our publications, please let us know by calling our toll-free number (1-888-441-2643) or e-mailing frbc@cpic.org

Staff Highlights



Daisy Lubag has been the Project Coordinator for FRBC for one year and has previous experience with study coordination and interviewing on a variety of health studies. She supervises the daily operation of the Family Registry and directs the field work of the telephone interviewers and interviewer/phlebotomists. Outside of work, Daisy finds tremendous joy in reading books (especially Jane Austen's), cooking, planning special events, attending live performances, and volunteering at her daughters' school.



Gauri Samant is the Research Assistant for the Family Registry. Among her many tasks, she communicates with our interviewers to make sure they have all the materials they need for conducting their interviews and blood draws. She also reviews and edits the many study documents when they come back to the office. She started with CPIC in 2007, volunteering her time in other departments and with other studies. Her hard work and dedication stood out, and in 2008 we were able to hire her for the Family Registry. Outside of work, Gauri likes to spend time reading and listening to music.



Debbie Serva has been with the Family Registry since 2003. As an interviewer/phlebotomist, she enrolls study participants, conducts interviews, and collects biospecimens for both the Family Registry and LEGACY studies. Outside of work, Debbie enjoys playing golf, fishing, gardening, skiing, and hiking. She and her husband have also enjoyed the experience of hosting exchange students from Japan.



Sonja Godfrey is also an interviewer/phlebotomist and has been with the Family Registry since 2005. She has considerable previous experience working on studies involving children, which made her a natural when we began the LEGACY study. In Sonja's own words: *"Working for the Cancer Prevention Institute affords me the opportunity to 'give back' and make a difference in lives with research. I especially love the one-on-one relations I build with the participants. This job is a joy and very rewarding."* Sonja has two children, both of whom are her pride and joy.



Jessica Heredia is a bilingual telephone interviewer with the Family Registry. She is responsible for interviewing women from many interesting backgrounds, but a large percentage of women she recruits for the Family Registry are Latina. In Jessica's own words: *"I consider this to be very important because I feel that together we are making an impact on what the medical community knows about this particular population, which will not only benefit us in the present, but will help future generations understand how cancer affects our families."* When not at work, Jessica enjoys cooking and baking.

Extended Follow-up Continues

A big thank you to the more than 2,500 Family Registry participants who have completed their extended follow-up interview! We are in the process of contacting all participants who have been with the Family Registry for five years or more to complete this interview. If you haven't been contacted yet, we will be calling you. The telephone interview takes approximately 30 minutes to update the demographic, reproductive, behavioral and medical information you provided to us when you first joined the Family Registry.

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rounds of follow-up. The girls have shown a lot of interest in actively participating in research and making a difference. We are seeking additional girls and mothers who are interested in participating in LEGACY. Let us know, if you are interested.

Pubertal development is important in breast cancer. It has long been known that women who started menstruating at an early age have a greater risk of developing breast cancer than those who start menstruating at a later age. Research has shown that physical activity, body size, nutrition, and genetics influence at what age a girl starts menstruating. However, not all factors are known that influence the start and tempo of pubertal development in girls. By studying these and other early-life factors in LEGACY, we aim to gain new information that can ultimately be used to develop breast cancer prevention strategies for girls and young women. Prevention is so much better than cure!

We are grateful to the Family Registry participants and their daughters for their participation and for their willingness to refer families with young girls who are not part of the Family Registry.

If you would like to learn more about the LEGACY study or if you and your daughter live in the San Francisco Bay area and are interested in participating, please call Enid Satariano (510-608-5025) or our toll free number (1-888-441-2643).

Returning Unsigned Consent Forms

Some of you may have completed questionnaires and provided blood or saliva samples, but have not returned your signed consent forms to us. We would like to use the valuable information you have provided, but we must have your signed consent in order to do so. If you have misplaced your form or have concerns about any part of it, please call our toll-free number (1-888-441-2643) or e-mail us frbc@cpic.org.



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 frbc@cpic.org

A Plea for Outstanding Diet Questionnaires

If you have not yet completed and returned the Diet Questionnaire, you are not alone. However, we hope you will do so soon! This questionnaire provides important information for addressing a number of questions related to breast cancer, such as whether vitamin D and other nutrients or foods can help prevent breast cancer.



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