10-year Follow-up is Winding Down

More than 3,400 of our Family Registry participants have completed the 10-year follow-up interview. We thank each one of you! Your continued participation is immensely valuable and much appreciated. There are still some participants we were not able to contact, and we would still like to hear from those individuals. If you have not heard from us recently, have moved to a new address, or have a new phone number, please let us know. We are now gearing up for the next phase of the Family Registry and we would like to include all our participants from the San Francisco Bay Area and their family members living elsewhere.

Gearing Up for the 15-year Follow-up

Advances over the past two decades have opened the door to new possibilities for personalized medicine and cancer prevention. For example, the discovery of *BRCA1* and *BRCA2* gene mutations has resulted in more appropriate targeting of preventive and screening strategies. Alterations in other genes that affect breast cancer risk are also being rapidly identified. This information is promising for use as part of personalized medicine.

Despite these medical advances, many important questions remain unanswered for women with a family history of breast cancer, both those with an identified genetic mutation, as well as the majority of women with a family history of breast cancer who do not carry a gene mutation.

New Funding to Continue Our Work

In 2011, the National Cancer Institute provided new funding for the six international sites of the Breast Cancer Family Registry to address some of the unanswered questions regarding the prediction of breast cancer risk in women from families with one or more affected family members. With the new funding, we will continue to follow over 12,000 breast cancer families from the USA, Canada, and Australia who are enrolled in the Family Registry, including over 4,000 families from the San Francisco Bay Area. In the next two years we will send a short mail questionnaire to over 30,000 family members, some of whom have participated in the Family Registry since 1996.

We count on your participation! Only with your help will we be able to answer important questions such as: What is a woman’s absolute risk of breast cancer given her age, family history, reproductive history and mutation testing results? What potentially modifiable lifestyle factors may lower a woman’s risk of developing breast cancer, given her family history? For those women who have a personal history of breast cancer, what can they do to lower their risk of developing a second cancer?

With your help, the Family Registry will produce important new information that will help us develop actions a woman may take to lower her risk of developing breast cancer.

The new questionnaire will ask each family member to provide updates regarding changes that may have taken place since we last spoke with you. It is important for us to hear from you even if you feel that you do not have any changes to report.
A Message from our Research Director
Dear Northern California Family Registry and LEGACY Girls Study Participants:

What if we knew what women at increased risk of breast cancer due to their family history could do to reduce their risk? What if certain risk-reducing actions could be adopted at a young age? Two new studies initiated last year will investigate these questions.

We received funding by the National Cancer Institute to conduct the 15-year Follow-up Study of participants in the Breast Cancer Family Registry. Many of you have participated in the Family Registry for more than 10 years, and we are very grateful for your continued support. With the new funding, we will be able to continue follow-up of the 12,000 breast cancer families enrolled in the Family Registry for another 5 years, including over 4,000 families from the San Francisco Bay Area. In the next 18 months you will receive a mail questionnaire which will take less than 10 minutes to complete.

We also received funding to expand the Family Registry cohort into the younger generation. The LEGACY Girls Study will enroll the young daughters of Family Registry participants and follow them for 5 years. For comparison, we will also enroll and follow girls from families without a history of breast cancer. In the last few months five Family Registry centers in the USA and Canada have enrolled over 200 girls between the ages of 6 and 13 years. Our goal is to enroll 900 girls by the end of 2012. You can learn below about how you can help us meet our goal.

Both of these new studies will collect important new data that will help us learn more about breast cancer prevention efforts. Your participation makes a big difference and we count on you! Thank you, Esther M. John, Ph.D.

The LEGACY Girls Study is in Full Swing
The LEGACY Girls Study is now launched! In the past few months, we have enrolled over 200 girls from the USA and Canada in the 5-year study. Please see the interview with one of our participating daughters and her mother from the Bay Area. This landmark study, funded by the National Cancer Institute, will examine how lifestyle, environment, and biology affect the growth and development of young girls and teens. We hope to learn how these factors affect women’s health later in life. A big thank-you to the girls and their parents who participated in our LEGACY pilot studies, and who have now joined the 5-year study. Our goal is to enroll 270 girls from the Bay Area, along with 630 girls from New York, Philadelphia, Salt Lake City, and Toronto, Canada. We would appreciate your help to meet our goals!

Girls between the ages of 6 and 13 years and their parent/guardian are eligible to participate in this study, regardless of their family history of breast cancer. This could be your daughter, granddaughter, niece, or the daughter of friends and acquaintances that you think might be interested in participating in the LEGACY Girls Study. We will ask the parent/guardian to answer questions about their own health, thoughts and feelings about breast cancer and about their daughter’s health, growth and development.

We will also measure the daughter’s foot size, height, and weight and ask her to provide a urine sample and a small blood sample. If the daughter is 10 years or older, we will ask her to answer questions about her health, growth and development, and behaviors. Each part of the study is voluntary and takes place at the participants’ home or elsewhere at their convenience. Please give us a call today at 1-866-878-5098 or 510-608-5025 to get more information regarding this new and exciting study. Take a look at our website www.legacygirlsstudy.org, meet the study staff, and share the website with your daughter and other mothers with girls between the ages of 6 and 13 years. If you would like to receive a study brochure for other families, please let us know.
A Personal LEGACY Girls Study Experience:
From LEGACY Mom Marilyn

Why did you decide to participate in the LEGACY Girls Study?
Because it is something that I have a great personal interest in. Cancer has touched me personally both with the loss of my mother 26 years ago and because I am a survivor of 8 years. I want to do whatever I can for my daughter’s future.

With young girls involved in many activities, why did you decide to make the LEGACY Girls study a priority?
I was intrigued by the opportunity to participate in a study with my daughter. I wanted her to be part of learning more about breast cancer and contributing to the possibility of one day preventing or curing it. Our daughters are our future and this is the most important aspect of the study to me.

How was your overall experience with the study appointment?
I thought the appointment went very well. The interviewer did a great job. She was very kind and related well to my daughter and was not pushy. Jyairrah really struggled with the blood draw. She wanted to give a blood sample but was afraid. Ultimately she didn’t do the blood sample this first time, but it was a good experience and she certainly might give blood in the future.

How do you feel about recommending your friends to participate in LEGACY Girls Study?
I think it is a great idea to include other moms. I provided a list of mothers who might want to participate.

From LEGACY Daughter Jyairrah

Why did you decide to participate in the LEGACY Girls study?
Because I like to experience different things.

How was your overall experience with the study appointment?
It was fun and I liked talking to Shanika about what it is like to be a nurse compared to a doctor.

Did you give a blood sample? Would you be willing to do it again?
I did not give a blood sample this time but I will next time.

Based on the first visit, do you think you will stay involved for the whole study (5 years)?
Yes, I will.

We gave a Target gift card for the first visit. Are there other types of gift cards you would like to receive in the future?
I liked the Target card.

A New Addition to our LEGACY Team:
Shanika Anderson, Interviewer/Phlebotomist

Hi LEGACY families! I am grateful to be one of the newest additions to the LEGACY Girls Study staff. I was born and raised in California. I recently moved back to the Bay Area from San Diego, where I worked as a Phlebotomist for the Naval Medical Center. It was my pleasure and honor to serve the Navy men and women that serve us. Before that, I worked as a preschool teacher in Alameda. I was the morning teacher for 24 four-year olds. I recently graduated from the Nightingale Nursing Program and am anxiously waiting to take my State Boards.

I’m looking forward to meeting and working with all of you on this very important project.
Follow-up… continued from page 1

The questionnaire will be short and should take less than 10 minutes to complete. Rather than calling everyone by telephone, we will send the questionnaire by mail. This will allow you to answer the questions at your convenience and return the completed questionnaire in a stamped return envelope. We greatly appreciate your continued help! Some of you have participated in the Family Registry for the past 15 years. The Family Registry is truly a very unique research effort worldwide.

In the next 5 years we will continue to keep you informed about the Family Registry through our annual newsletter and other communications. We are also very interested in finding out whether you and other participants would prefer to receive such information via email. Furthermore, we are exploring the possibility of replacing our annual short telephone interview with an online questionnaire that you could fill out on your home computer. Our 15-year follow-up questionnaire includes a question on your preference. You can also let us know at 1-888-441-2643 or 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 us at frbc@cpic.org

Meet our office research staff: (top) Daisy Lubag, Meera Sangaramoorthy, Jocelyn Koo and (bottom) Cody Ramin (now at Harvard School of Public Health), Gauri Samant, Connie Cady, Enid Satariano, Maria Talosig-Garcia.
Not pictured: Nina Santos.