



The Northern California Family Registry for Breast Cancer Studies

SUMMER 2003

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RESEARCH & CANCER
CARE RESOURCES

Northern California
Cancer Center:

www.nccc.org

Living Beyond Breast
Cancer:

www.lbbc.org

National Breast Cancer
Coalition:

www.natlbcc.org

National Alliance of Breast
Cancer Organizations:

www.nabco.org

Susan G. Komen Breast
Cancer Foundation:

www.komen.org

For support:

www.cancerhopenetwork.org

www.thewellnesscommunity.org

The Family Registry For
Breast Cancer's Toll Free

Number:

1-888-447-2643

Newsletter Editor:
K. Hannah

Focus on Participants

Leonor Rocha is married and the mother of two young boys. She is also, at age 36, a breast cancer survivor. The Family Registry's Project Coordinator, Amy Monaco, spoke with her about the importance of a family's support and the insight gained from having survived cancer.

In April of 2000, when she found out she had cancer, she told her parents the news right away, but then came the more delicate task of explaining her illness to her children who were then only four and eleven years old. She decided to tell only her older son. "I think that was the hardest part. We went to the front of the house, we were sitting on the stairs and I (said) 'I need to tell you this...you're going to see your mom in different changes. I went to the doctor and they told me I have cancer.' 'What's cancer, mom?' he asked and I told him it's not like a surgery where you're going to get well right away. I'm going to go through a lot of things and I want to have your support. Your little brother's only four and he doesn't understand...you understand all these things.'



Leonor and her husband

She's had young girls approach her amazed she was diagnosed so young. She hands them little pamphlets on breast self-exams and tells them to always check themselves. "It doesn't matter your age, just do it! Don't forget..."

her pet rabbit was having babies. "I just put my slippers on and forgot my hat and I ran outside." It was the first time her brother had seen her without hair. As a show of solidarity, that same night he went home and shaved his head. "That night he came over and I had to shave him because he didn't want the little stubs. Then he said, 'Sit down. Let me cut those little shreds you have.' While her brother shaved his hair, her husband vowed not to cut his until she was well. "He promised a saint in Mexico when I got well he would cut his hair and leave it there (as an offering)."

While undergoing chemotherapy, surgery and radiation, Leonor did little exercises to maintain the mobility of her arm, took herbal vitamins and indulged her penchant for face creams. "All those little things. I just spent a little more than usual," she laughs, "but it did me good."

As a hairdresser, she dreaded losing her hair from chemotherapy. She cut her waist length hair three times in one week. "It hurt me a lot. I had a few little hairs here and there and I didn't want to shave it." Out of embarrassment, she kept her head covered. Early one morning her brother came over and yelled for her to come outside because

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it's something to help in the future
...for others.*

Her reasons for participating in the Family Registry are simple:

"This is an opportunity to help people...it's something to help in the future—for others." When asked what she'd like to say to others with breast cancer, she urged, "Always be positive. I think people who are more positive get through it faster and just plain get through it. And for the families? Just always be by their sides, support them as much as you can. She's had young girls approach her amazed she was diagnosed so young. She hands them little pamphlets on breast self-exams and tells them to always check themselves. "It doesn't matter your age just do it! Don't forget. It's an important thing for you to do for yourself."

Where Does My Biospecimen Go?

Each biospecimen that our phlebotomists collect is sent to the Coriell Institute for Medical Research, an internationally known not-for-profit, biomedical research institution. In the late 1940's, the Institute's founder, Lewis Coriell, M.D., Ph. D. played a major role in bringing the Salk polio vaccine to the public by using cell cultures to study human viral

diseases. Impressed with Dr. Coriell's work, local business leaders helped him to establish a basic research facility in 1953. Dr. Coriell and his colleagues at the Institute pioneered many cell culture techniques that are now standard throughout the world. They used these techniques to make advances in understanding cancer and infectious diseases. Each biospecimen arrives anonymously at Coriell with only a study ID number attached. It is then given a confidential bar code and a tracking number. Researchers have begun to use the DNA from these biospecimens, along with the questionnaire data, to better understand the role of genetics and lifestyle factors in the development of breast cancer.

If you have questions or would like to read more about the Coriell Institute, log onto <http://coriell.umdj.edu/index.html>

The Latest Numbers:

As of June 2003, these six international sites...

- Northern California Cancer Center,
Union City, California
- Columbia University,
New York City, New York
- Fox Chase Cancer Center,
Philadelphia, Pennsylvania
- Huntsman Cancer Institute,
Salt Lake City, Utah
- University of Melbourne,
Melbourne, Australia
- Cancer Care Ontario,
Toronto, Canada

...which are all participating in the Breast Cancer Family Registry have enrolled 11,540 families and collected interview data from 26,592 family members and blood samples from 18,364 individuals.

	NCCC Participants	All the Centers Combined
Total number of Families	2,823	11,540
Total number of family members	5,450	26,592
Total number of blood samples collected	3,888	18,364

What's Happening Now

As the Family Registry grows into an ever richer source of information, the interest in and demand for use of the data and biospecimens also increases. At present, there have been 84 applications for research grants, 64 of which have already received funding and are ongoing, and 10 of which are from the Northern California Cancer Center. Among these is a new grant headed by Dr. Alice Whittemore of Stanford University, which will look at environmental effects on people with some genetic alterations. The study is funded by the National Cancer Institute and will involve the analysis of data from all six centers.

New Faces:

This year, the Family Registry for Breast Cancer welcomes two new interviewer/phlebotomists: Norma Ramirez-Sidhu (pictured left) and Debbie Serva (right). Together they have over twenty years of experience in the medical profession.



Two New Follow-Ups:

Starting in late Summer 2003, FRBC will begin its extended follow-up, contacting participants who've been involved with the study for five years in an effort to update information regarding lifestyle and medical history. Additionally, we will start follow-up with relatives of participants. The purpose is to maintain the most current and accurate information available.

Participant Enrollment Progress for the Family Registry

To date, the Family Registry has enrolled 371 minority participants, nearing half of the projected goal. The Registry continues to recruit minority women with breast cancer to ensure a true representative sampling of the Bay Area's multicultural population.

	Enrolled to Date: 6/3/2003	Study Goal
African-American	118	278
Latino	100	384
Chinese	73	166
Japanese	23	48
Filipino	57	103
Total	371	979



Chiao-Jung Tsai, a third year doctoral student in epidemiology at Stanford University, joined the Northern California Cancer Center's Family Registry in February of 2003. She has a great interest in "exploring the risk factors of familial breast cancer, particularly among the minority populations" and is currently helping with various quality control tasks and analysis of the registry's data.

Do you have questions about:
Clinical Trials?
Support Groups?
Access to Mammograms?
Cancer Care?

Call the Cancer Information Service

1-800-4-CANCER

for free information
or visit

<http://cis.nci.nih.gov>

and click on the Live Help link
from 9a.m.-5p.m.

Among available literature topics:

- Breast Cancer in the Workplace
- Guide to Forming Spanish-speaking Support Groups
- How You Can Make a Difference

As of April 14, 2003 the Privacy Rule of HIPAA (the Health Insurance Portability and Accountability Act) went into effect. Your health care provider must obtain your authorization before they can give out certain health information for research. The Family Registry for Breast Cancer now has an additional consent form which the participant must sign if access to medical records, tissue samples and pathology reports is to be granted for use by future researchers.

Celebrating Five Years

The Family Registry is fortunate to have Angela Black, interviewer and phlebotomist, on our team. This year marks Ms. Black's fifth year with us. In 1998, she was drawn to the Registry because she wanted to learn more about breast cancer and felt it would be a way to help those affected. "Working for breast cancer studies has been the most inspiring job I have had," says Ms. Black. She prides herself on being what she calls a "people person" and indeed, the Family Registry has significantly grown due in large part to her efforts and determination. She has worked with nearly 500 participants and their families.

When she isn't committing time to her work, Ms. Black loves music and plays the piano in her church on Sundays.

Everyone at the Registry knows what a tremendous asset she is and hopes she'll stay with us for another five years!



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CHANGE OF ADDRESS?

The Northern California Family Registry wants to keep you up to date for several years to come. Please clip and save this postage paid postcard and return it to us if your name or address changes.

Your name:

Your new address:

New phone number:

Effective as of: _____

Please use this space to tell us what you would most like to see in future issues of the newsletter:

Thank You Very Much!

Ongoing Study: Stress and Breast Cancer Survival

In 1999, Dr. David Spiegel, former Family Registry co-investigator, conducted a pilot study on needs assessment in women whose relatives have breast or ovarian cancer. Dr. Spiegel, Professor and Associate Chair of Psychiatry and Behavioral Sciences at Stanford University, is now conducting a new study funded by the National Institute on Aging and the National Cancer Institute that will examine breast cancer patients' stress levels in relation to their cancer's progression as well as how the support of loved ones affects hormonal activity.

Women who live in the Greater Bay Area who have had metastatic or recurrent breast cancer are welcome to participate. Participation will include:

- Coming to Stanford Medical Center once a week for one month
- Taking a series of medical tests involving saliva & blood samples
- Agree, that after one year, you will provide follow-up information and saliva samples

Participants may receive up to \$500. If you would like to be involved or if you want to find out more information, please contact:

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email: mparineh@stanford.edu



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