



The Northern California Family Registry for Breast Cancer

SUMMER 2004

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Update on the Northern California Family Registry

In the Fall of 1996 the first participants were enrolled in the Northern California Family Registry. As of May 2004 more than 2,400 families have participated. The goal of the Northern California Family Registry is to enroll 2,650 families by October 2005. The information provided by Northern California participants, along with that of participants at five other collaborating family registries in New York, Utah, Pennsylvania, Ontario, Canada and Australia, has been consolidated into one large resource, known as the Breast Cancer Family Registry. Together, information from well over 20,000 participants is available to address many unanswered research questions regarding the causes, prognosis and treatment of breast cancer.

The development of the Breast Cancer Family Registry has already resulted in the initiation of more than 80 research projects among the participating sites and within the greater international research community and has already

produced many publications. Breast Cancer Family Registry researchers include epidemiologists, molecular biologists, molecular geneticists, clinicians, geneticists, genetic counselors, statisticians, pathologists and behavioral scientists. In this issue we report on some of the ongoing and planned projects.

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WE'RE MOVING!

Beginning October 11, 2004, the Family Registry for Breast Cancer, along with the entire Northern California Cancer Center, will have a new address:

The Northern California Cancer Center

2201 Walnut Avenue

Fremont, CA 94538

Main Phone: (510) 608-5000

Fax: (510) 608-5095

Please note our toll-free number remains the same:

1-888-441-2643

For more information about FRBC go to www.nccc.org
Click on: research & training, research programs, then click on Family Registry for Breast Cancer

We express our appreciation to the many people who have contributed to our Northern California Family Registry. The registry would not be possible without the thousands of women and men who agreed to take time from their busy schedules to meet with our interviewers and phlebotomists. We are truly grateful for their ongoing participation.

Focus on Minorities

Female breast cancer incidence rates vary significantly by country and by population subgroups within countries, whether defined by race/ethnicity, culture or socioeconomic status. Similarly, stage of disease at diagnosis, length of survival and treatment received show variation across population subgroups. However, there have been relatively few studies on the causes of breast cancer and the outcome of women living with breast cancer that have included an adequate number of minority women.

NORTHERN CALIFORNIA FAMILY REGISTRY FAMILIES AS OF MAY 2004	
Non-Hispanic White	871
African-American	421
Hispanic	401
Chinese	328
Filipino	244
Japanese	89
Other	91
TOTAL	2,445

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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

Highlighting a few of the studies using the resources of the Breast Cancer

Family Registry...Studies such as these are only possible because of the many women in the Breast Cancer Family Registry who have completed the interviews and provided a blood sample. The findings from these studies will benefit many other women who are not part of this important program.

Breast Cancer Risk From Genes, Environment and Lifestyle

Recent scientific work has led to a better understanding of human genes as they affect cancer. Genes are found in our cells and they affect characteristics we inherit from our parents, like our eye color. Genes are also important in controlling how cells grow. When certain genes are damaged they may lose the ability to control the rate at which cells grow, and if they grow too fast, cancer develops. Some of these faults (mutations) are passed to us by our parents, which may increase our risk of developing certain cancers.

Ten years ago scientists discovered two major breast cancer genes, *BRCA1* and *BRCA2*. Although major faults in these genes are relatively rare, studies have shown that women who are born with a faulty gene have a much greater risk of developing breast or ovarian cancer later in life. But not all women who have a faulty gene develop the disease. This suggests that there must be other important genes or lifestyle and environmental factors that influence a woman's chance of developing breast or ovarian cancer.

In 2003 the National Cancer Institute funded a new study led by Dr. Alice Whittemore at Stanford University that will investigate whether some of the known risk factors for breast cancer work in the same way in women who have an inherited fault in *BRCA1* or *BRCA2*. The study will focus on five factors that are potentially modifiable, including oral contraceptive use, radiation exposure to the chest, alcohol consumption, cigarette smoking, and physical activity.

From other studies we have learned the following regarding these factors: oral contraceptives use and cigarette smoking don't appear to influence the risk of developing breast cancer; risk is increased in women who drink alcohol every day, or had frequent radiation exposure to the chest, particularly if they were treated with radiation before age 20; and risk is reduced among women who are physically active. It is important to find out what women with a faulty gene can do in order to reduce their risk of developing breast or ovarian cancer.

Alcohol and Breast Cancer

Previous studies have reported that daily alcohol consumption increases the risk of developing breast cancer. There is considerable interest in understanding this association because alcohol consumption is both common and a behavior that can be changed. Dr. Julia Knight at the Ontario Family Registry has recently received funding to examine whether variation in the genes involved in the way the body processes alcohol could modify the effect of alcohol on breast cancer risk. This is important because alcohol may be a much more important risk factor for some groups of women. Understanding this would help identify those subgroups for special counseling to reduce alcohol consumption. This study will include data collected from approximately 10,000 women in the Breast Cancer Family Registry (including Northern California) and will be the largest study on this topic to date.

Understanding Survival

Since many more women are surviving breast cancer, it is important to understand why some women do better after their diagnosis than other women. Why, for example, does breast cancer come back in some women and not in others? Learning the answers to this and other questions will help to develop better treatment procedures and follow-up after a diagnosis of breast cancer. Dr. Pamela Goodwin at the Mount Sinai Hospital in Toronto and colleagues in Australia and Northern California are studying the effects of a variety of different factors, including those related to the *BRCA1* gene and microscopic characteristics of breast tumors on cancer recurrence, new breast cancers, and longevity. This study will include data collected from about 1,600 women in the Breast Cancer Family Registry.

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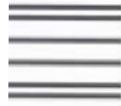
One important feature of the Northern California Family Registry is the racial diversity of the San Francisco Bay Area. Northern California families account for almost 60% of the 2,346 minority families in all of the Breast Cancer Family Registry.

The Northern California Family Registry is committed to including women of all races in the study. However, we have found that some minority women who are contacted about participation are less likely to agree to the interview, provide a blood sample and permit contact with their eligible relatives. We would like to request the help of those of you who are participating to assist us in improving the participation among all women. If you know a woman who was invited to be part of the study but who had concerns, please encourage her to call our office. We welcome the opportunity to answer questions about the family registry and our interviewers and phlebotomists are very flexible about making appointments to fit participants' schedules.

We would like to request the help of those of you who are participating to assist us in improving the participation among all women. If you know a woman who was invited to be part of the study but who had concerns, please encourage her to call our office.

If you have other suggestions for encouraging minority women to take part, please call Enid Satariano or Amy Monaco at the Family Registry (1-888-441-2643). By interviewing and obtaining blood samples from as many women as possible among those selected for the study, we hope to learn more about the causes of breast cancer and to achieve a better understanding of differences in breast cancer between different population groups.

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Follow-Up Activities to Extend to Relatives

We are continuing with our annual telephone follow-up interviews with participants to ensure we have the most current and accurate information available. In February 2004 we extended the follow-up to include participating relatives. We are re-contacting all relatives who completed the epidemiology questionnaire and asking them to complete an interview to update the information they originally provided.



A Walk in the Park

The Oakland A's Breast Cancer Awareness Day 2004 will benefit the Northern California Cancer Center. Survivors, family members and fans are invited to show their support for breast cancer research and education on Sunday, September 12, by purchasing a ticket to "A Walk In The Park" which will take place during a special pre-game ceremony before the A's take on the Cleveland Indians at 1:05 p.m. The \$25 fee includes a Plaza Level Outfield ticket to the game and the opportunity to walk around the field with hundreds of others who are joined together to make a difference. Proceeds from "A Walk In The Park" will benefit the Northern California Cancer Center and the American Cancer Society. For more information on how you can join the Oakland A's in their efforts to strike out breast cancer, please call (510) 638-4627 or log on to oaklandathletics.com.

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:

Email Address:

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!

Introducing...

The Family Registry is pleased to welcome two new multilingual interviewers to our staff. Each comes to us with a wealth of experience in their field.



Mei-Chin Kuo, interviewer and phlebotomist, received her MSN from the University of Wisconsin and has worked as an independent care provider for patients in need of long-term care. She has also worked as a research nurse at the Children's Mental Health Center in Taiwan and speaks both Taiwanese and Mandarin.



Fluent in both Spanish and English, interviewer Laura Long returns to NCCC after working two years as a public health educator for the Stanislaus County Health Services. Ms. Long formerly worked for the Cancer Information Service at NCCC where she helped to answer questions from cancer patients and their families. She received her BA in biology from UC Berkeley.



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