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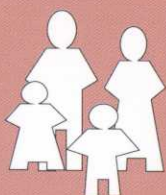
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NORTHERN CALIFORNIA



Family Registry

FOR BREAST CANCER STUDIES

NEWSLETTER, WINTER 1999

Introducing the Family Registry... Thank you for taking part in the Northern California Family Registry for Breast Cancer! We begin our fourth year encouraged by the enormously positive responses we have received from over 800 families in the San Francisco Bay Area. With your help, we will gather information from approximately 3,000 women and men that will be the foundation for future research. Thanks to the generous participation of so many women, men, and families, we are very gratified to see our Family Registry growing into a vital research resource.

The information provided by Family Registry participants will allow researchers to more closely identify patterns of cancer within families and relationships with inherited and lifestyle factors. While the results of this type of research will accumulate gradually over several years, we will report in these pages new research directions and findings as they become available. We hope you and all of our participants will find this newsletter to be a useful source of health information.

Inside....

- * Research directions
- * Protecting confidentiality
- * Studies being conducted

What is the Family Registry ? In 1996, the National Cancer Institute funded six research institutions to establish the "Cooperative Family Registry for Breast Cancer Studies" (CFRBCS). The six institutions are: the Northern California Cancer Center (NCCC) in the San Francisco Bay Area; Columbia University in New York City; Huntsman Cancer Center in Salt Lake City; Fox Chase Cancer Institute in Philadelphia; Cancer Care Ontario in Toronto, Canada; and University of Melbourne in Melbourne, Australia. The information collected by these six Registries will

be consolidated, so that together information from over 6,000 families will be available for research.

The Northern California Cancer Center is the parent organization of the Northern California Family Registry, which is the only US population-based registry in the CFRBCS. This means that participants are recruited from the entire population, not just from genetic clinics, allowing us to better study the impact of cancer on the population as a whole. Furthermore, the Bay Area's broad ethnic diversity allows us the unique opportunity to address health concerns specific to African American, Latino, and Asian American communities.

How Does the Family Registry Work ?

Over the past three years, interviewers from the Northern California Cancer Center have contacted thousands of women and men in the Bay Area and asked them to complete a short phone interview. Depending on responses given to questions about occurrences of breast, ovarian, and childhood cancer in the family, over 800 people (to date) have enrolled in the Registry and have allowed us to contact certain members of their families.

(continued on pg. 2)



Family Registry Staff: Back Row, L-R: Dee West, Carol Young, Trisha Harasty, Jolyn Smith, Marcela Magaza, Colleen O'Grady, Samantha Chen. Middle Row, L-R: Tami Eilenberger, Enid Satariano, Victoria Wylan, Gwen Moore, Connie Cady, Rogeline Amo, Esther John, Jeanne Boxley. Front Row, L-R: Debbie Sohn, Angela Black, Claudine Reyes, Margaret Canfield. Not Pictured: Sally Glaser, Alice Whittemore.

How Does the Family Registry Work ?

(cont. from pg. 1)

The Northern California Family Registry includes:

- Women diagnosed with breast cancer before the age of 35
- Women diagnosed with breast cancer between the ages of 35 and 64 who also have a history of breast, ovarian, or childhood cancer
- Men diagnosed with breast cancer
- Women and men who have not had cancer but whose family members have been diagnosed with breast cancer
- A selection of women and men who have had breast cancer but who do not have a history of breast cancer in their families
- A selection of women and men without breast cancer.

Interviews regarding family history of cancer, exercise, diet, past medical history, and other factors are conducted by our staff of seven interviewers, who also collect blood specimens from participants. This effort keeps them travelling throughout the Bay Area and keeping in touch via phone or mail with the participants' family members living as far away as Hawaii, Alaska, and Newfoundland, Canada. The interviewers recontact participants about once a year to gather information about treatment, update information we have already collected, and introduce upcoming research projects that might be of interest to participants.

Progress to date includes selecting over 800 families and completing data collection for over 1,700 family members. These numbers are growing daily, as we approach our goal of contacting more than 1,200 families and 3,000 family members by the spring of 2000.

Protecting Confidentiality

The decision to share personal information with research scientists may not be an easy one. We at the Family Registry want to be sure that participants feel fully informed and comfortable when making this decision. Here are a few of the procedures we follow to secure the confidentiality of the information we are collecting:

- Each participant is assigned a unique Study ID number, and family members are linked together using a Family ID number. Researchers who analyze the blood samples, diet and lifestyle information, and family medical history will know the study participant only by his or her ID number, never by name. The list of corresponding names and addresses is kept separate, accessible only to select research staff here at the Northern California Cancer Center.
- Study findings will only give results for the study population as a whole, never for individuals.
- We hold a Certificate of Confidentiality, issued by the National Institutes of Health, which states that we cannot be compelled to release any identifying information about our participants. No court or insurance company can force us to release that information.
- If, at some time, researchers indicate that they would like to contact certain Family Registry participants for a more extensive study, we will approach these participants with an explanation of the new study and ask them whether they are interested in being contacted about the new study. Only if participants tell us they are willing to be contacted for the new study will we release names and addresses of participants to other researchers.

If you have questions or concerns about confidentiality, please call us toll-free at 1-888-441-2643.

In the News...

Clearer, More Detailed Mammograms

The New York Times reported on November 30, 1998 that a new digital mammography device may be on its way to FDA approval. The very detailed images made possible by this newly developed technique may enable greater accuracy in mammography and earlier detection of cancer -- especially when breast tissue is naturally dense, such as in young women. In dense breast tissue, it can be difficult to distinguish a mass of cancer cells using traditional mammography. In contrast, a digital image might be magnified and viewed more closely by a radiologist.

New Breast Cancer Prevention Trial

The Northern California Cancer Center, with collaborators at Stanford and UCSF Medical Centers, has been selected to participate in the Study of Tamoxifen and Raloxifene (STAR), beginning in 1999. The opening of the STAR trial follows closely on the heels of a recently completed trial of breast cancer prevention using Tamoxifen. In this study, researchers found a significant decrease in the incidence of invasive breast cancer among women who were at a high risk for developing breast cancer and who were taking Tamoxifen, compared to those who did not take the drug. The new study will examine whether Raloxifene, a drug similar to Tamoxifen, is also effective in preventing cancer in women who do not have the disease and whether it offers any benefits over Tamoxifen. STAR is designed to include 22,000 postmenopausal women 35 or older who have not had breast cancer but are at an increased risk for developing breast cancer. The trial will be conducted for 5 years with follow-up examinations for at least 7 years. Anyone interested in this trial can learn more about it by calling the Northern California Family Registry at 1-888-441-2643 or the Cancer Information Service at 1-800-4-CANCER.

Do you have questions about:

- Tamoxifen and Raloxifene?
- Support Groups?
- Access to Mammograms?
- Cancer Care?

Call the Cancer Information Service
1-800-4-CANCER

A free information line

What Kinds of Studies are Underway?

Here are two examples of research projects that are currently making use of the information collected for the Family Registry and through the collection of some additional information:



**David Spiegel, MD,
Stanford University**

Needs Assessment in Women Whose Relatives Have Breast or Ovarian Cancer

Dr. Spiegel is Professor of Psychiatry and Behavioral Sciences at Stanford University School of Medicine and is Director of Stanford's Psychosocial Research Laboratory.

Dr. Spiegel's research is funded by a number of leading research and charitable foundations, including the National Institute of Mental Health, National Cancer Institute, American Cancer Society, John D. and Catherine T. MacArthur Foundation, and others.

Dr. Spiegel is now working with a group of Family Registry participants, including sisters, mothers, and daughters of women who have had breast cancer. Participants in the study are asked to complete psychological and social questionnaires to evaluate stress levels, mood, coping and social support, and perception of cancer risk. Dr. Spiegel and his research team hope that this project will provide data that will form the basis of a larger study to address the needs of high-risk women by providing group support.

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**Barbara Koenig, PhD,
Stanford University**

A Study of Social and Ethical Issues Confronting Families Enrolled in a Family Registry for Breast Cancer

Dr. Koenig, an anthropologist who studies contemporary medicine, is Executive Director and Senior Research Scholar at the Stanford University Center for Biomedical Ethics. With her colleagues at the Center, she recently established the Stanford Program in Genomics, Ethics, and Society, an effort that seeks to research and analyze the clinical challenges presented by developments in the field of molecular genetics.

The purpose of Dr. Koenig's project is to understand how people experience having breast cancer in their family and being part of a Family Registry. Dr. Koenig and her research team also hope to learn about people's attitudes and beliefs regarding illness, health care, and genetics as they relate to cancer. Dr. Koenig's study is expected to get underway in early 1999. She hopes that the information gained from her study will be used to develop better counseling and support services for people who have breast cancer in their families.

Research and Cancer Care Resources on the World Wide Web:

- Northern California Cancer Center
<http://www.nccc.org>
- National Cancer Institute
<http://www.nci.nih.gov>
- UCSF's Cancer Care Center
Clinical Trial Page
<http://bcc-ct.his.ucsf.edu>
- National Alliance of
Breast Cancer Organizations
<http://www.nabco.org>
- Stanford University's
Community Breast Health Project
<http://www-med.stanford.edu/CBHP/>

LET US HEAR FROM YOU!

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

Your name: _____

New address: _____

New phone number: _____

Date effective: _____

Is there something specific you would like to see addressed in future issues of the newsletter? _____

THANK YOU

FRBC 1650

THE NORTHERN CALIFORNIA CANCER CENTER 25TH ANNIVERSARY PROGRAM

NEW DIRECTIONS IN BREAST CANCER

SPEAKERS TO INCLUDE:

Richard Klausner, MD,
Director, National Cancer Institute

Mary Claire King, PhD,
Prof. of Epidemiology,
University of Washington

Alice Whittemore, PhD,
Director, Epidemiology, NCCC,
Prof. of Epidemiology,
Stanford University

- AND OTHERS -

WHEN

Wednesday
March 24, 1999
8:30 a.m. to 5:00 p.m.

WHERE

Palace Hotel
Two Montgomery Street
San Francisco, California

RSVP

For more details,
Call 1-888-441-2643

JOIN US IN CELEBRATING 25 YEARS IN THE COMMUNITY



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