



The Northern California Family Registry for Breast Cancer Newsletter

Published Research from the Northern California Family Registry

Many of our Family Registry participants ask about results of our on-going work. The data and biospecimens contributed by our participants have led to many publications over the past 12 years. The following list highlights a few of the recent publications. We hope this shows you the value of your continued participation in the Family Registry.

1. Medical radiation exposure and breast cancer risk: finding from the Breast Cancer Family Registry.

John et al., International Journal of Cancer, 2007. It has long been known that high doses of radiation, particularly before age 20 years, increases breast cancer risk. Less is known about the effects of common low-dose diagnostic medical radiation. This study explored whether frequent diagnostic radiation exposure increases the risk of developing breast cancer. Results showed a two- to three-fold

increased risk of breast cancer in women who had been treated with radiation for a prior cancer, or who had multiple diagnostic chest x-rays for tuberculosis before the age of 20 years. These findings confirm reports from previous studies. We also found an increased risk in women who had frequent radiation exposure for pneumonia. Routine chest x-rays were not associated with breast cancer risk. Importantly, there was no evidence that the effects of routine chest x-rays were enhanced in women with a family history of breast cancer.

2. BRCA1 and BRCA2 mutation carriers, oral contraceptive use, and breast cancer before age 50.

Haile, et al., Cancer Epidemiol Biomarkers Prev, 2006. Many studies have shown that oral contraceptives (OCs) protect against ovarian cancer and endometrial cancer. With regard to breast cancer, most recent studies found no evidence that OCs increase risk, except for some older studies that reported increased risks among young women who began OC use at a young age. This Family Registry based study explored whether OC use increases breast cancer risk in women less than 50 years of age who carry a mutation in *BRCA1* or *BRCA2*. Since carriers of such mutations are at increased risk of developing breast

cancer, it is important to identify lifestyle factors that may further increase or lessen their risk. We found that OC use for one year or longer did not increase breast cancer risk in *BRCA1* mutation carriers. Among women carrying *BRCA2* mutations, there was an elevated risk among those using OCs for 5 years or longer. Relatively few studies have addressed the role of OCs and other lifestyle factors in mutation carriers. More studies are needed to confirm this finding and to better understand why the effect of OCs may be different in *BRCA1* versus *BRCA2* mutation carriers.

3. An inverse association between ovarian cysts and breast cancer in the Breast Cancer Family Registry.

Knight, et al., International Journal of Cancer, 2006. Polycystic ovary syndrome may increase the risk of breast cancer, but no studies have assessed whether ovarian cysts, which are common in women of reproductive age, are associated with breast cancer risk. This study using data from the Breast Cancer Family Registry is the first to address this question in a very large study. We found that a diagnosis of ovarian cysts was associated with a 30% lower risk of breast cancer. A second study by Dr. Knight confirmed this finding.

For a more complete listing of publications go to

<http://epi.grants.cancer.gov/CFR> . ☺

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The Community Education Program at the Northern California Cancer Center



**NCCC's Community Education Staff:
 Pamela Ratliff, Elaine Neufeldt and Pamela Priest-Naeve**

Despite the fact that hundreds of articles are written every month about cancer – in magazines, newspapers, internet sites and other publications – most people know little about cancer. For the most part, no one really wants to know about cancer until they have to... when it becomes personal for themselves or a loved one. When that happens, good quality, trusted information is needed to help make important decisions.

The NCCC Community Outreach Program provides health information in words that the public can understand. The intent is to help individuals make informed choices about their health and healthcare. Staff does this through annual conferences, community seminars, websites, work site seminars, publications, community health exhibits, special projects, telephone information resource services, and an extensive network of collaborators and educators. The topics covered include

those related to wellness as well as illness and include issues of communication, estate planning, employment, and relationships with family, friends, health care providers, employees and employers, to name a few.

CancerCalendar is a website that was recently launched as a public service by the NCCC Community Education Program. This free online resource provides information on cancer education programs and events throughout the greater San Francisco Bay Area for patients and families, health care professionals, and the general public. NCCC's upcoming programs can be found at CancerCalendar.org or www.nccc.org. On the right is a sampling of some of the programs coming up in the next few months. For more details on these and other programs, go to <http://cancercalendar.org>



Healthy Holiday Eating

Greta Macaire, RD will lead this session on how to prepare holiday meals in a healthy manner. Participants will learn the secrets of “sneaky” cooking to help increase fiber and reduce fat. They will also leave with some healthy and delicious holiday recipes.
 Nov 13, 2007, 4:00pm - 6:00pm
 UCSF Comprehensive Cancer Center, San Francisco
 Paul Asfour
CancerResource@ucsfmedctr.org

What Now? Living With New Normal After Cancer Treatment

A look at the medical, psychosocial, lifestyle and financial issues faced by patients and families after cancer treatment.
 Dec 1, 2007, 8:30am - 3:30pm
 Mission Bay Conference Center, San Francisco
education@nccc.org
www.cancercalendar.org
 1-888-315-5988

7th Annual Allison Taylor Holbrooks/ Barbara Jo Johnson Breast Cancer Conference

Program includes: Clinical cancer updates; breakout sessions: sexual side effects of cancer treatment, reconstruction, side effect management, DCIS, metastatic disease, Stage 1 and 2 treatment issues; and more. This conference is very popular and sells out.
 Mar 1, 2008, 8:00am - 3:30pm
 Golden Gate Club, San Francisco Presidio
education@nccc.org
www.cancercalendar.org
 1-888-315-5988

Family Registry Data Staff

Sarah Vande Voorde moved to California from Oregon and has been with the Family Registry for one year as our Research Assistant. She communicates with our interviewers to ensure that each participant completes the correct questionnaires. When the questionnaires and other study materials are returned to the office, she updates the study tracking system with all the information and prepares them for data entry. Sarah enjoys spending her free time outdoors, hiking or running.

Meera Sangaramoorthy is an epidemiologist who works on the Family Registry as well as another large breast cancer study. She is responsible for the biospecimen and genetic data at our site and works closely with Dr. John on the analysis of data that results in scientific publications from the Family Registry. Meera recently relocated to California from Baltimore, Maryland, where she worked in lab-based environments. She enjoys hiking and playing tennis, and is a fan of the performing arts, especially dance.

Connie Cady has been with the Family Registry since 1996. Though her duties have changed over the years, she is now our data manager, overseeing the study tracking system and managing the data from all the many sources. “It is gratifying to see how the study has grown and evolved,” she notes. Connie has two children, ages 10 and 7. She enjoys coaching their sports teams. She also enjoys volunteering and fundraising at their school.

Jocelyn Koo is a biostatistician who prepares the submission of data from questionnaires and other sources to the central database. The data, identified by study ID only, are combined with data from the other five family registries in the US, Canada, and Australia, and used by scientists in their research. Jocelyn also analyzes data from the Family Registry as well as other studies. Outside of work, she swims, struggles to understand the rules of soccer at her kids’ games, and irregularly practices origami and piano.

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Family Registry Data Staff: Jocelyn Koo, Meera Sangaramoorthy, Sarah Vande Voorde and Connie Cady

Extended Follow-up is for Everyone

We have begun contacting those of you who joined the Family Registry five or more years ago. We would like to update the demographic, reproductive, behavioral and medical information you provided to us. There will also be a number of new questions on such topics as breast cancer screening and use of certain medications. The telephone interview will take approximately 30 minutes. You will be asked to complete this extended follow-up JUST ONCE within the next four years.

Please Say Yes to Blood Donation!

We need your blood donation. We really do! Using blood samples along with the questionnaire data is the only way the Family Registry can answer important questions about the role of genetics and lifestyle factors in the development of breast cancer. If you are among those who have been reluctant to donate your blood, we hope you will join the more than 300 participants who overcame their reluctance! Please email us at frbc@nccc.org or call our toll-free number 1-888-441-2643 to arrange for your donation. Together we will contribute to better ways of preventing and treating breast cancer!

Genetic Studies of Breast Density: Recruitment Nearing Completion

We are very close to completing the data collection phase for this new study which began last year. A big THANK-YOU to the more than 700 sisters who have returned their study forms to us. If you have been invited to participate in this study and have not yet completed the forms, NOW is the time to do so. It takes only a few minutes. If you have misplaced your packet we can mail you another one (just call us at 510-608-5025), or we can complete the forms with you over the phone if that is easier for you. ☺

Community Representatives on the Breast Cancer Family Registry

The Steering Committee serves as the main governing board of the Breast Cancer Family Registry. It is made up of the Principal Investigator and the Co-Principal Investigator from each of the six family registry sites as well as community representatives. The community representatives are very important contributors to the Breast Cancer Family Registry. They are breast cancer survivors who advise Family Registry researchers on behalf of the participating families. Their dedication stems from their own experiences. Currently, Sylvia Rickard and Gerda Evans serve as the community representatives.

Sylvia Rickard lives near Salt Lake City, Utah. She has been a patient advocate with several community



breast cancer organizations for more than 15 years, ever since her own diagnosis with breast cancer. In addition to

serving on the Steering Committee of the Breast Cancer Family Registry, she has also been very active as a Legislative Team Leader with the National Breast Cancer Coalition. Ms. Rickard also chairs the South West Advisory Committee of Redes en Accion, a program designed to reduce the cancer burden in Hispanic populations.

Gerda Evans lives in Melbourne, Australia. Despite her training as an oncology nurse Ms.



Evans was astonished when she, two sisters and a first cousin, were diagnosed with breast cancer within a few years of one another. A paternal aunt had died from breast cancer many years earlier. When one of her sisters had a recurrence of her cancer, she decided that she should increase her

knowledge of this disease. Ms. Evans became actively involved with Breast Cancer Network Australia as the Victorian State Representative and the family cancer representative on several committees. In addition to the Breast Cancer Family Registry, she is also a Community Representative for the Kathleen Cunningham Foundation for Research into Familial Breast Cancer (kConFab) in Australia. ☺

Tell Us Your Story...

Let us know how breast cancer has affected your life, good or bad, and share with us why you're committed to being part of the Northern California Family Registry. Your story may be printed in our next newsletter or on the website that we are developing.

Mail to Northern California Family Registry, c/o Enid Satariano, 2201 Walnut Avenue, Suite 300, Fremont, CA 94538-9903 or email frbc@nccc.org.

For a list of publications and research findings already made possible by your participation, please visit <http://epi.grants.cancer.gov/CFR/>



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