



The Northern California Family Registry for Breast Cancer

Summer 2005

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Protecting the Personal Information of Family Registry Participants

We have received a number of calls from participants over the past year asking how their personal information is kept safe and secure from identity theft. It is an important question because participants provide detailed information to the Family Registry to help researchers better understand how to prevent and cure cancer. The Family Registry and the Northern California Cancer Center take the protection of personal information very seriously and safeguard your personal information in a number of different ways. These include assigning identification numbers to keep names separate from other information, adhering to strict guidelines for the release of data, and maintaining an armory of computer security systems to protect against viruses and other forms of infiltration.

“When individual data are submitted to the central database...they are submitted in an anonymous format that is completely stripped of personal information.”

SPECIAL BULLETIN

This year we are enclosing the first annual newsletter of the Cooperative Breast Cancer Family Registry, a collaboration of six family registries in the U.S., Canada and Australia. Highlights include:

- An update from the NCI Program Officer
- A spotlight on Dr. Esther John
- Breast cancer research activities

Cooperative Breast Cancer Family
Registry Web site:
<http://epi.grants.cancer.gov/CFR>

We keep names and information separate by assigning each person in the Family Registry a unique identification number. Your information and samples are labeled with this number and any names, addresses and phone numbers are stored separately from all other study information. When individual data are submitted to the central database that stores information collected by all six family registries, they are sent in an anonymous format that is completely stripped of personal information such as names, addresses and phone numbers. In addition, only authorized employees of the Northern California Family Registry who have signed a legally binding confidentiality agreement have access to the personal information.

Once the anonymous data are stored at the central database, they become available to researchers whose projects have undergone a rigorous evaluation by both an Ethics and a Scientific Review Committee. At no time will your name or address or any identifying information ever be released without your stated permission. If an approved researcher would like to collect additional information, we will contact you to explain the study and let you decide whether to participate and allow the researcher to contact you.

“At no time will your name or address or any identifying information ever be released without your stated permission.”

VISIT US ON THE WEB:
www.nccc.org >
Research and Training >
Research Programs >
Family Registry for
Breast Cancer

Are you looking for a
support group or
have questions about
treatment options?
CANCER INFORMATION
SERVICES
1-800-4-CANCER
for free information

Contact
ENID SATARIANO
PROGRAM MANAGER
esataria@nccc.org
Office: (510) 608-5025
Toll Free: (888) 441-2643

NUMBER OF FAMILIES RECRUITED FOR THE NORTHERN CALIFORNIA FAMILY REGISTRY AS OF JUNE 2005	
African-American	509
White, non-Hispanic	869
Hispanic	488
Chinese	369
Filipino	268
Japanese	97
Other	99
Total	2699

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NEWSLETTER EDITOR
JANELLE COMMINS

In addition to keeping names and interview data separate, the Northern California Cancer Center employs a team of database administrators and network engineers who maintain the security of the Family Registry database. Joyce Harvey, Network Server Administrator, explains that NCCC's network security plan is a multi-tiered system that includes a strong firewall; data and database security; restricted remote access; frequent password changes; and security software that is updated daily to guard against new threats, with anti-virus software that constantly monitors all systems for virus

“An independent security firm tests our network security by intentionally trying to hack into the network from outside the organization.”

and virus-like activity, spyware, key loggers and other intruders. On a quarterly basis, an independent security firm tests our network security by intentionally trying to hack into the network from outside the organization.

The Age of Information is here. For cancer research this means broader access to participants and allows for more productive research while simultaneously fueling a growing concern for information theft at the individual level. The Family Registry and the Northern California Cancer Center take this concern for information security seriously and we do all we can to ensure that names, addresses and phone numbers are protected daily in both systematic and technical ways. Your participation over the years has allowed the Breast Cancer Family Registry to grow into one of the largest research collaborations in the world, and we will continue to expand

as technology progresses with your privacy in the forefront of our minds. We appreciate your continued confidence.

New Studies

Within the next few months three new studies will get underway. You may be contacted and invited to participate.

LEGACY Study (Lessons in Epidemiology and Genetics of Adult Cancers from Youth):

The Family Registry is interested in possibly expanding the participating families to include family members under the age of 18 years in order to investigate important early events in breast cancer. This may be a time period when prevention strategies might produce the greatest results. We will participate in a registry-wide pilot study with adult-parent participants to evaluate their interest and concerns about their children being asked to participate in interviews and provide a blood sample as part of the youth cohort.

Ethnic and Cultural Differences in Cancer Risk Beliefs and Behaviors:

Little is known about how people from different cultural backgrounds experience and respond to information about cancer and the role of genetics in health and disease. We will participate in a registry-wide pilot study that will address these issues in preparation for a larger study that will help us develop culturally sensitive materials to facilitate the use of genetic data for cancer prevention and treatment.

Genetic Studies of Breast Density:

The National Cancer Institute has funded a new 5-year study to find out which genes influence the amount of dense breast tissue as seen on a mammogram. Such information may help us to predict a woman's risk of developing breast cancer. We will contact family registry participants to ask for permission to borrow their mammograms which will be scanned by computer to determine the density of breast tissue.

Putting Faces to Names: Spotlight on the Project Coordinator & Follow-up Interviewers



Shanta Russell has been the Project Coordinator for the Family Registry for almost one year and has experience in study coordination and interviewing on health studies. She directs the activities of all the telephone and field interviewers. Shanta is working on a Master's degree in Public Health Administration, does volunteer work with teen girls and enjoys playing soccer.



Each year we re-contact participants to ensure we have the most current and accurate information available. Most of the follow-up interviewing is done by three of our Telephone Interviewers and many of you have talked to them on an annual basis for a number of years.



Margo Noble has been with the Family Registry for more than five years. She has completed more than 4,500 follow-up interviews with 1,700 participants. When she's not on the phone, Margo enjoys biking and classical music.



Dorien Silverstein has been with the Family Registry for 2 ½ years and does most of the follow-up interviews with participating relatives. She has completed more than 1,100 interviews. She has three young grandchildren who are fortunate to have Dorien living near them.

Jolyn Smith has been an interviewer for many years in the Bay Area and works on multiple projects. She has completed almost 2,400 follow-up interviews with 1,400 family registry participants. Jolyn likes to travel and is spending her vacation this year in Greece.



The Breast Cancer Family Registry Newsletter

A project sponsored by the National Cancer Institute

About B-CFR



NCI Cancer Family Registry Support Staff (left to right): Mr. Keith Richardson, Dr. Edward Trapido, Dr. Virginia Hartmuller, Ms. Emily Dowling, Dr. Alysa Lesemann, Dr. Daniela Seminara, and Ms. Linda Anderson (not pictured: Ms. Valeria Rodriguez).

This year marks the 10th anniversary of the Breast/Ovarian Cancer Family Registry (B-CFR), and there is much to celebrate! Thanks to you, enrollment in the registry reached a high of 12,507 families and 37,724 individuals as of early 2005. This makes the registry one of the largest resources available to researchers to study the causes of breast and ovarian cancer.

We are delighted to have this opportunity to share with you news about the current work of the registry. There has been a dramatic rise in the number of research projects that rely on it. Through scientific collaborations with researchers all over the world, 80 projects have been or are being conducted. More than 110 reports about the studies and their findings have been published in scientific journals. The topics covered in these reports

range from information about the molecular characteristics of tumors, to the genetics of breast and ovarian cancer, to the best ways to communicate results from genetic testing. In this newsletter, we share with you news about some of the most recent findings to emerge from these studies.

We expect the coming years to be as exciting as the first and anticipate many more important scientific contributions. Currently, the registry is moving away from general recruitment to focus on enrolling additional minority families and family members of individuals who are enrolled. B-CFR also plans a follow-up of registry participants enrolled between 1995 and 2000 to obtain updated information on areas such as diet, family history, lifestyle, and environmental factors. This information will help us address important

Minority Recruitment



Dr. Esther John

The National Cancer Institute (NCI) places considerable emphasis on studying cancer in minority populations because the racial/ethnic differences in the risk for cancer are not well understood. Recruitment of minorities into the B-CFR has been a major focus and more than 2,700 families of

African, Hispanic, or Asian ancestry now are enrolled. However, to gain important knowledge about the interaction of genes, environment, and other lifestyle factors related to risk for breast cancer, large numbers of minority families are needed.

In the next phase of recruitment, the B-CFR will focus on the enrollment of African-American and Hispanic families. This effort

Participating Sites:

Australian Breast Cancer Family Registry

Metropolitan New York Registry

Northern California Cooperative Family Registry for Breast Cancer

Ontario Familial Breast Cancer Registry

Family Risk Assessment Program at Fox Chase Cancer Center

Utah Cooperative Breast Cancer Registry at Huntsman Cancer Institute

issues in the development of breast and ovarian cancer.

B-CFR's guiding aim is to answer important questions about the causes of breast and ovarian cancer that can be translated into development of better ways to prevent and treat these diseases. This crucial work would not be possible without the help of you and your family.

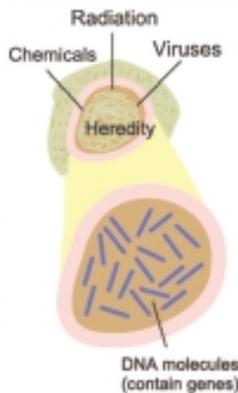
Once again, thank you,

Daniela Seminara, Ph.D., M.P.H.

NCI Program Officer #

is headed by Dr. Esther John, Principal Investigator at the Northern California Cancer Center. By the year 2010, the B-CFR intends to triple the number of African-American families and double the number of Hispanic families enrolled, making the registry an even more valuable resource for answering critical questions about breast cancer in minority populations. #

Behind the News is a user-friendly, online educational resource developed by the National Cancer Institute to better inform the public about cancer-related topics. The excerpt below is from the Understanding Cancer portion of the site. To reach Science Behind the News, go to www.cancer.gov/science/behind.



Genes and Cancer

Chemicals (e.g., from smoking), radiation, viruses, and heredity all contribute to the development of cancer by triggering changes in a cell's genes. Chemicals and radiation act by damaging genes, viruses introduce their own genes into cells, and heredity passes on alterations in genes that make a person more susceptible to cancer. Genes are inherited instructions that are regions within DNA molecules. Each gene allows a cell to make a specific product—in most cases, a particular kind of protein. Genes are altered, or "mutated," in various ways as part of the mechanism by which cancer arises.

B-CFR Research Highlights

DNA Repair Deficiency and Breast Cancer Risk - Researchers have found that cells from sisters with a history of breast cancer have significantly diminished capacity to repair damaged DNA compared to cells from sisters without a history of the cancer. DNA damage can result from environmental exposures, such as cigarette smoke or diet, or it may occur through normal cell division. While there are no methods of increasing the body's ability to repair DNA, individuals can reduce exposure to known cancer causing agents and maintain a healthy lifestyle. This study was conducted by Drs. David Kennedy and Regina Santella of Columbia University and colleagues. The study participants were from Metropolitan New York Registry of Breast Cancer Families.

Kennedy DO et al. DNA repair capacity of lymphoblastoid cell lines from sisters discordant for breast cancer. *J Natl Cancer Inst* 2005; 97(2):127-32. #

Oral Contraceptive Use in *BRCA1* and *BRCA2* Carriers - Through the B-CFR, researchers have conducted the first large, population-based study focusing on the relationship between oral contraceptive use and risk for

breast cancer in women with *BRCA1* and *BRCA2* gene mutations. Past studies have suggested that oral contraceptive use is associated with a small increased risk for breast cancer, but the risks for mutation carriers were unclear. This new study found no evidence of an association between use of current low-dose formulations of oral contraceptives and early-onset breast cancer risk (diagnosed before age 40) for either *BRCA1* or *BRCA2* gene mutation carriers. In fact, the risk for early-onset breast cancer may be reduced for *BRCA1* gene mutation carriers. In light of these findings and given that other research suggests that current formulations of contraceptives may reduce risk for ovarian cancer among mutation carriers, their use by women with *BRCA1* and *BRCA2* gene mutations does not appear to be harmful. The study was conducted by Mr. Roger Milne and Dr. John Hopper of the University of Melbourne, and Dr. Alice Whittemore of Stanford University, and other B-CFR investigators.

Milne RL et al. Oral contraceptive use and risk of early-onset breast cancer in carriers and noncarriers of *BRCA1* and *BRCA2* mutations. *Cancer Epidemiol Biomarkers Prev* 2005;14(2):350-6. #

Cancer Family Registry Model Expands to Latin America

Hispanics/Latinos have a lower incidence and death rate from several major cancers, including breast cancer, when compared to non-Hispanic whites. This is true for Hispanics/Latinos who are recent immigrants as well as first generation offspring. Compared to non-Hispanic whites, however, Hispanics/Latinos have higher rates of other cancers, for example, stomach, cervical, and liver cancer. It is important to examine the role of genetics, environment, and acculturation in different Hispanic/Latino populations to understand the factors underlying this phenomenon.

A large number of cancer epidemiology studies involving Hispanic/Latino populations are conducted in North America, which represents only a fraction of this population worldwide. There are a wide variety of dietary, lifestyle, and environmental exposures, as well as genetic variations among the people in Latin American countries. Therefore, Latin American-based cancer family registries can provide valuable new information on factors that contribute to or protect against cancer. Scientists at NCI, including Dr. J. Fernando Arena and Dr. Daniela Seminara, are explor-

ing the possibility of expanding the CFR model to Latin America. This would enable cancer risk factor comparisons of several Hispanic/Latino populations and provide more information on cancer etiology in different environments. Understanding differences by comparing populations around the world will contribute to our overall knowledge of cancer epidemiology, prevention, and treatment. #



Dr. J. Fernando Arena

Other Research News: Molecular Genetic Test

Research supported by NCI suggests that a new genetic test can predict the risk of breast cancer recurrence and may identify women who will benefit most from chemotherapy. The test examined the levels of expression (either increased or decreased) of a panel of cancer-related genes. The results were used to predict whether estrogen-dependent breast cancer will recur. Researchers used the results of the panel to group women according to

risk of recurrence, and found that 51 percent of the women were in the low-risk group, 22 percent were in the intermediate-risk group, and 27 percent were in the high-risk group.

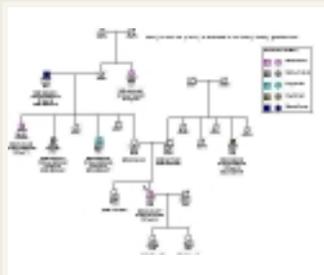
Therefore, women with low recurrence scores may derive only minimal benefits from chemotherapy. Because this study looked only at women with breast cancer that responded to estrogen and had not

spread to the lymphnodes, all types of breast cancer cases were not included. For more information about this study, see <http://www.cancer.gov/newscenter/pressreleases/breastgeneassay>.

Paik S et al. A multigene assay to predict recurrence of tamoxifen-treated, node-negative breast cancer. *N Engl J Med* 2004;351(27):2817-26. #

Know Your Family History

Registry participants can request a picture of their family health history. The picture depicts a family tree with names, vital statistics and medical information. Participants can get a family tree in two ways: 1) Enter family health information into “My Family Health Portrait” available on the National Institutes of Health Web Site at <http://www.hhs.gov/familyhistory>. The information is used to create a document that shows the health and medical relationships between individuals. 2) Request a family tree from us (see picture) depicting names, vital statistics and cancer diagnoses as reported by participating family members. Simply return the response card on the back page clearly marked “Family Tree Requested” with your full name and mailing address.



A Little Blood Goes A Long Way

One of the most important pieces of information collected from participants in the Family Registry comes in the form of a blood sample. From a blood sample of about three tablespoons we obtain DNA, the body’s genetic material, which is used to learn more about the influences of genetic alterations on breast cancer risk. The DNA is stored as a resource for future studies approved through the Family Registry.

While many studies of breast cancer have been done in non-Hispanic white populations, very little is known about the role of breast cancer genes, such as *BRCA1* and *BRCA2*, in minority women. As one of the largest scientific resources of minority families, the Family Registry has the potential to answer important questions about the genetics of breast cancer in minorities. Questions like: “How common are *BRCA1* and *BRCA2* genetic mutations in minorities?” and “What specific changes in *BRCA1* and *BRCA2* genes affect breast cancer risk in minorities?” The only way the Family Registry can answer crucial questions like these is to collect blood samples from our participants.

We express our many thanks to participants who have already donated a blood sample to the Family Registry and encourage participants who have not agreed to a blood draw to do so at their next follow-up. Family Registry staff includes experienced phlebotomists who can schedule blood draws at times that fit our participants’ schedules.

Your cooperation is helping us answer important questions!



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Take “A Walk in the Park” with the Oakland A’s

Join the Oakland A’s as they take on breast cancer and the Texas Rangers on Sunday, September 25, at 1:05 p.m. for the Seventh Annual Breast Cancer Awareness Day. Survivors, family members and fans are invited to show their support for breast cancer research and education during a special pre-game ceremonial walk around the park before the game.

Last year, this event raised \$125,000 for cancer research and education. A portion of the proceeds from this year’s game will benefit the Northern California Cancer Center. For more information, please call:

(510) 638-4900 x2329

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, phone number 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 or to request your family tree.

Thank You Very Much!

Family Matters

A central goal of the Breast Cancer Family Registry is to understand how breast cancer is related to patterns of family cancer history. To do this we collect information from women with breast cancer and also from certain relatives of those women.

Family members not only share many of the same genes, they may also share a common environment and often have similar lifestyle factors like diet and physical activity. Learning more about relatives of women with breast cancer helps us to understand how genes and environment and lifestyles interact to affect breast cancer risk, and why some family members may develop breast cancer while others do not. Contacting the relatives of women with breast cancer also gives the Family Registry an opportunity to learn about cancers in the family that the original participant may have forgotten or not known about, creating a more complete picture of a family's cancer history.

Relatives are an essential resource to the Family Registry. We encourage all participants to talk to their relatives about the Family Registry and let them know what an important role they can play in our efforts to learn more about breast cancer and to encourage them to participate in our studies.



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