2008

CGN Annual Newsletter

Dear CGN Participants,

The Cancer Genetics Network (CGN) would like to take this chance to thank you for your commitment and participation in this important research project and to update you on some of the studies underway. The CGN was created to study the emotional, psychological, genetic, and clinical issues in care of people with a family history of cancer. Today, the CGN has over 25,000 participants throughout the United States (U.S.). With your help, this unique research program is helping us learn more about cancer**.**

On May 1, 2007, the National Cancer Institute (NCI) renewed the CGN by awarding a contract to Massachusetts General Hospital (MGH), a Harvard partner institution, as the coordinating center. The network consists of the coordinating center at MGH as well as 14 other institutions across the U.S., including Huntsman Cancer Institute. We are very excited about the renewed support and commitment from NCI and this new phase of the CGN.

If we contact you about joining one of the CGN studies, we hope that you will consider becoming a participant. With your support, we are making important progress toward improving the understanding of the natural history, screening, diagnosis, and treatment of cancer with the goal of preventing and curing this disease.

Thank you,

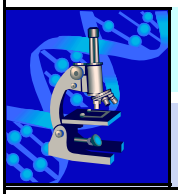
Anita Kinney, Ph.D., R.N.

Know your family history!

Having a family history of cancer increases your risk of getting cancer, but knowing your family history can help you to lower your cancer risk. For example, your lifetime risk of developing colorectal cancer increases 2-4 times if one of your first-degree relatives (parent, sibling, or child) has been diagnosed with this disease. Your risk increases even more if your first-degree relative was diagnosed under the age of 60, or if you have more than one close relative who has been diagnosed with colorectal cancer.

Most Americans understand that their family's health history is important to their health, but the reality is that few of us actively collect this vital information. Family members share genes and often have similar environments, lifestyles, and habits. You may ask, "I cannot change my genes, so why do I need to know my family's health history?" The answer is, even though you cannot change your genes, you can change your behaviors. Many common diseases, including some types of cancer, result from the interaction of your genes with environmental and behavioral risk factors that **can** be changed. Behaviors which may lower your disease risk include increased physical activity, improved eating habits, and smoking cessation. Along with these behavioral changes, if you know your family's health history, then you and your health care provider can discuss prevention and screening options appropriate for your cancer risk level.

The Cancer Genetics Network encourages you to take time at a family gathering to discuss your family's history of disease. It may not be the most comfortable subject, but it gives you the information you need to identify your risk for certain types of cancer, along with many other diseases, and **that** can be comforting. To assist with this process, the U.S. Department of Health and Human Services (HHS) has developed a free computer program that organizes important health information and which can be printed for you to take to a health care professional so they can help you determine your disease risk. This computerized tool is called "My Family Health Portrait" and can be downloaded at **http://www.hhs.gov/familyhistory/**.



Updates on CGN Projects

Genetics Projects

Biorepository Project:

Research has shown that cancer in families can occur because of similar lifestyles and habits or because of inherited genes.

Collecting blood specimens to study DNA allows scientists to study the genes that may lead to cancer. This in turn may help identify causes of cancer in people with a high cancer risk and lead to new early detection, prevention, and treatment methods. For this purpose, the CGN has recently started to collect DNA for a central biorepository, which is a place to store blood specimens.

This biorepository project is focused on collecting DNA from men and women with a family history of multiple cancers in the same person, cancers that are diagnosed at an early age (under 50), and/or people who have had rare cancers. When a blood sample is provided to the biorepository, personal information is kept private; there is no link between the DNA and the participant's name.

We want to extend our gratitude to those who have donated their blood samples and provided us with additional family health information. This information is very valuable to our research.

Genetic Modifiers of BRCA1 and BRCA2 (GEMS)

Researchers at Duke University and several other hospitals enrolled women into this study. The goal of the study is to find environmental and genetic factors that influence the risk of getting breast cancer in women who have been tested for mutations in the BRCA1 and/or BRCA2 genes. A mutation in these genes increases the chance of developing breast cancer and ovarian cancer. In the future, such research may lead to a deeper understanding of breast cancer genetics, which could lead to tailored screening and treatment programs.

Over 1,200 women have enrolled in GEMS and through the study participants were asked to:

- Complete a 20 minute phone survey
- Donate a blood sample
- Allow researchers to access pathology report and genetic testing results

This study is closed for recruitment and is currently in the analysis phase.

Screening Projects

Ovarian Cancer Screening Study (ROCA):

This study has enrolled more than 2,300 women at high risk for ovarian cancer during the last seven years at over 20 sites around the country. Women who have advanced ovarian cancer have higher levels of a chemical called CA125 in their blood. This study examines whether periodic testing of CA125 levels in high-risk women could help with the early detection of ovarian cancer. The study is no longer enrolling new subjects. Analysis of the study data is planned in 2008.

Behavioral Projects

Family Health Promotion Project (FHPP):

This is an ongoing study to evaluate different methods for encouraging screening among individuals in families affected by colon cancer. FHPP has successfully enrolled 632 participants from the CGN or Colon Cancer Family Registry. Three CGN sites recruited participants into this study: the Universities of Colorado, Utah, and North Carolina. Accrual has ended but follow-up of the study participants is ongoing. We have begun analyses of the data which will continue throughout 2008.

BRCA1/2 Mutation Carriers: Screening and Intervention

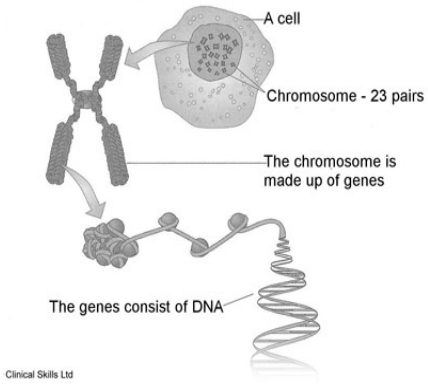
Women with mutations in the *BRCA1* and *BRCA2* genes have greatly increased risk of developing breast and/or ovarian cancer. The lifetime risk of breast cancer is up to 80% for U.S. women carrying these genetic mutations and the lifetime risk of ovarian cancer is up to 40% for BRCA1 mutation carriers and up to 20% for BRCA2 mutation carriers. There are methods to reduce cancer risk so individuals with a family history of cancer may want to consider genetic testing. Healthy women who carry BRCA1 and BRCA2 mutations may want to discuss prevention and screening options with their physician.

Because the ovaries lie deep in the body, it is difficult to detect ovarian cancer until women experience symptoms, at which point, it may be too late to treat the disease effectively. Symptoms may include: abdominal bloating, urgent or frequent urination, difficulty eating or feeling full quickly, and pelvic or abdominal pain. Often these symptoms are dismissed by the woman or her physician because so many other conditions can cause these symptoms. For this reason, women with BRCA1/2 mutations who do not plan to have more children may consider having their ovaries removed. Studies show that prophylactic oophorectomy (removal of ovaries) in BRCA1/2 mutation carriers reduces the risk of ovarian cancer by 85-95% and decreases the risk of breast cancer by 50% or more.

There are several proven methods of screening for breast cancer, including magnetic resonance imaging (MRI), mammography, and ultrasound. Most women are familiar with mammography, but the use of MRI for breast cancer screening is relatively new. A MRI is painless and uses magnets to produce signals that create an image of part of the body. Current research supports the practice of yearly MRI tests and yearly mammograms for women at high risk for breast cancer. Breast removal (prophylactic mastectomy) is another preventative option which studies show reduces the risk of breast cancer by as much as 90%. It is important to note that there are many alternatives to mastectomy, including prophylactic oophorectomy in premenopausal women, heightened surveillance (through frequent mammography and MRI tests), and the consideration of prescription medications.

Overall, women with mutations in the BRCA1/2 genes are encouraged to schedule yearly screenings and appointments with physicians.

Genetic Testing—What is it?



Our bodies are made up of millions of cells. Inside the cells are chromosomes (23 pairs) and on the chromosomes are genes. The genes control our growth and how our bodies work. They are also responsible for many of our physical characteristics (eye color, blood type, height). Sometimes there is a change or mutation in a gene which stops the gene from working properly. Genetic testing helps identify changes in particular genes. If a genetic mutation is identified, the term "mutation carrier" is used. In many cases, if several family members have been diagnosed with the same type of cancer, there is a chance the cancer may be due to a genetic change that has been passed on in the family. Family history, environmental factors, and behavioral factors are also crucial in determining risk (see article on page 1). The decision to undergo genetic testing can be difficult and should be made in consultation with your physician and genetic counselor. To help locate a genetic counselor in your area, you can search the National Society of Genetic Counselors website at www.nscg.org (Modified from leaflet produced **by** EuroGentest, 2007).

In the News

Researchers have identified a combination of five gene variants (changes, not mutations) which increase the prostate cancer risk in men. In addition to family history, the combination of variants accounted for nearly half of the prostate cancer cases studied. Unfortunately, the variants do not identify which cancers need treatment or correlate with PSA levels. Until more is known, men should talk with their family about prostate cancer history and consult with their physician.

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Did you know…recent studies suggest that most Americans who should be getting screened for colorectal cancer do not. A study that followed Medicare beneficiaries from 1998-2004 found that only **25.4%** of people who should have been screened were in fact screened, even though Medicare covers these screenings. Men and women **over the age of 50** should have routine screenings for colorectal cancer. Earlier screening may be appropriate for individuals with a family or personal history of colorectal cancer.

Stay in Touch!

In order to make the CGN cancer research studies possible, it is critical that we maintain up-to-date family/cancer histories and contact information in our database. Please keep us informed of any changes in your health or the health of any of your family members, including recent medical procedures or findings, new cancer diagnoses, and deaths, as well as changes in contact information.

When you receive our follow-up mailing or phone call, it is important to respond, even if there are no changes. With your help in keeping our records current, our registry will continue to be a resource for cancer research.

The CGN would like to thank all study volunteers. Your participation is vital to the success of these and future cancer research studies.

For more information:

National Cancer Institute:
http://www.cancer.gov/

The Cancer Genetics Network:
http://hedwig.mgh.harvard.edu/cgn/front

National Comprehensive Cancer Network:
http://www.nccn.org/

American Cancer Society:
http://www.cancer.org/docroot/home/index.asp

The Cancer Information Network:
http://www.cancerlinksusa.com/