Cancer Genetics Network

Volume 1, Issue 1 2009 Annual Newsletter

GREETINGS FROM THE CGN

INSIDE THIS ISSUE:

SPECIAL POINTS OF INTEREST:

- The CGN has over 20,000 participants
- CGN participants have participated in 11 research studies, resulting in 48 publications
- The first participants have now been members of the CGN for nearly 10 years!

The Cancer Genetics Network (CGN), now in its 10th year, continues to be a rich resource for cancer investigators interested in the causes, outcomes, treatment, screening, and psychological aspects of cancer. **Your** participation and continued commitment to the CGN is directly linked to the Network's success.

Throughout your participation in the CGN, you have been contacted for annual follow-up. This year we have expanded the follow-up survey.

Researchers can use this new information to address scientific questions about cancer risk and prevention, and to develop follow-up care plans that allow for surveillance, prevention, and management of the long-term effects of cancer. Although this is a longer survey, it should take approximately 10-15 minutes to complete. We appreciate your time and effort in completing this expanded survey.

Sincerely,

Constance A. Griffin, MD
Principal Investigator

WHAT YOU'LL NOTICE AS 'NEW' ON THIS YEAR'S FOLLOW-UP

Cancer Treatment History: These questions will provide investigators with information about severity (stage) of any cancer diagnoses you have had and how the cancer was treated (surgery, radiation, chemotherapy, hormonal therapy). Information on treatment history will help researchers investigate possible long-term effects of cancer treatment.

Screening Tests: We provide a list of cancer screening tests and ask that, for each test, you tell us whether you have had the test, and provide information about your age when you had the test and whether the test identified anything abnormal. We are interested in knowing whether how often you have the tests or the result of these tests varies depending on whether a person has a family history of cancer.

Genetic Testing: We provide a table of available genetic tests and ask you to tell us if you have been tested and if you or anyone in your family tested positive for a genetic mutation. Genetic testing questions will help investigators design future studies that may focus on groups of people who test either positive or negative for a specific genetic mutation or syndrome.

General Health Conditions: These are conditions or symptoms that might be related to your risk for getting cancer or result from having cancer or being treated for cancer. We provide a list of conditions and for each one, we ask you to tell us whether you have ever had the condition and if so, to provide basic information about the diagnosis and treatment.

Reproductive History: Several questions have been added regarding menstruation, menopause, pregnancies, contraceptive and hormone use. We are interested in looking at the role of reproductive hormones in cancer.

Ovarian Cancer Awareness Ribbon

OVARIAN CANCER SCREENING STUDY - What have we learned so far?

The Risk of Ovarian Cancer Algorithm (ROCA) Study began enrolling women in May 2001. Women at increased risk for ovarian cancer due to family history of breast or ovarian cancer had blood drawn every 3 months while participating in the study. The blood samples were tested for the level of CA125, a blood marker that is elevated in some women prior to diagnosis of ovarian cancer. These CA125 levels, along with other information, were used to calculate an estimate of a woman's risk for getting ovarian cancer. If the risk estimate was higher than 1%, women were advised to have further screening tests. The goals of the study include determining the factors that affect a woman's CA125 level, and evaluating whether this approach to screening is effective.

2,353 women have enrolled in the study. The study team has determined that several factors affect a woman's CA125 level. Overall, CA125 levels are lower in women who have gone through menopause than in premenopausal women. Among premenopausal women, Asians, current smokers, current users of oral contraceptives, and women with irregular menstrual periods have lower CA125 compared to others. In postmenopausal women, African Americans, current smokers, those who have used fertility drugs or have had their ovaries removed have lower CA125.

Nine women were diagnosed with ovarian cancer during the study. Three of these cancers were present but previously undetected when the women enrolled. The remaining six cancers developed as the study progressed. Some of the cancers were detected when an increase in the woman's CA125 resulted in an elevated cancer risk estimate. Other cancers were detected during elective surgery to remove the ovaries, even when there was no increase in CA125 or the estimated risk of cancer. So far, the results suggest that this type of ovarian cancer screening could lead to earlier detection of ovarian cancer, but a larger study is needed to know for sure.

BRCA and *HER2/neu*….WHAT IS THE DIFFERENCE?

BRCA1 and *BRCA2* genes are in a group of genes called tumor suppressors. When they are functioning normally, cells in the body grow and divide at a normal rate. When there is a mutation (or change) to the *BRCA1* or *BRCA2* gene, uncontrolled cell growth can occur. Mutations in these genes are present at birth. These mutations can be passed down through either the mother's or father's side of the family. Women with mutations in the *BRCA1* or BRCA2 genes have greatly increased risk of developing breast and/or ovarian cancer.

HER2/neu, also called *HER2*, is a gene that signals cells to grow, divide, and repair. A change to the *HER2* gene is not inherited (passed down from your parents), but rather happens during your lifetime due to aging, wear and tear on your body, and possibly due to environmental factors. When a breast cancer is diagnosed, the tumor is tested to determine if it is *HER2* positive or *HER2* negative. *HER2* positive tumors may be treated with Herceptin, a targeted treatment to help reduce the overproduction of growth proteins. *HER2*-positive cancers don't seem to respond as well to Tamoxifen as *HER2* negative cancers. Therefore, knowing *HER2* status can be a useful marker to guide chemotherapy regimens.

Cancer Genetics In the news

* Researchers from Duke and Johns Hopkins have identified mutations in two genes related to malignant glioma, a class of brain tumors. In the future, the mutation may serve as a biomarker to help identify individuals who are likely to have better outcomes and receive different treatments. *(NEJM 2009 360:765-773).*

* Researchers have identified a gene (*GUCY2C*) that may better identify metastatic colorectal cancer and possibly the risk of recurrence. In patients where no cancer cells were found in the lymph nodes by biopsy, *GUCY2C* patients had a greater risk of earlier disease recurrence and a shorter disease-free survival time, compared with patients negative for GUCY2C. *(JAMA 2009; 301(7) 745-752).*

* A recent review article in the *Journal of National Comprehensive Cancer Network (2009, 7:193-201)* suggests that the addition of MRI may help evaluate the extent of breast cancer in women with newly diagnosed breast cancer.

* Researchers from the University of Pennsylvania studies investigated the outcomes of *BRCA* carriers who had undergone the preventative removal of ovaries and fallopian tubes. The researchers concluded that this procedure is strongly associated with reductions in the risk of breast, ovarian, and fallopian tube cancers in women who carry one of the *BRCA* mutations and that some women may benefit from this risk reduction strategy. *(JNCI 2009, 101:80-87)*

* A recent study by researchers at Fox Chase Cancer Center in Philadelphia found that men with *BRCA* mutations are unaware of their cancer risks. *BRCA+* men have the same chance (50%) as women of passing the mutation to their children. These men are at an increased risk for melanoma, prostate, pancreatic, and male breast cancer. If men have many family members with breast or ovarian cancer (diagnosed before age 40), they should talk to their physician and possibly consider genetic counseling. *(Journal of Genetic Counseling, 2009, 18:42-48.)*

CGN DNA Bank: For the Study of Familial Cancer

In the previous newsletter, we introduced the CGN Biorepository, which is now renamed the **DNA Bank**. To date, there are 411 CGN participants from 9 Centers enrolled in the DNA Bank.

The CGN DNA Bank is for individuals who have had cancer at an early age, multiple cancer diagnoses or have a family history of the same cancer in blood-related family members.

If you decide to join the DNA bank, you will give a blood or saliva sample once.

Your sample will be sent to Massachusetts General Hospital in Boston, MA. DNA will be extracted from your blood or saliva and stored for up to 20 years for use in future research. The DNA bank will allow researchers to study the genes that may lead to cancer.

***If** you are interested in providing your DNA to the DNA Bank or have more questions about this study, please contact the CGN DNA Bank Coordinator:*

(866) 593-8419
contactcgn@partners.org

Mid-Atlantic Cancer Genetics Network (MACGN)

Constance A. Griffin, MD
Johns Hopkins University
Baltimore, Maryland

Toll Free (877) 880-6188
Local (410) 502-9232
Fax (410) 502-7670
www.MACGN.org

DIRECT-TO-CONSUMER ADVERTISING OF GENETIC TESTING

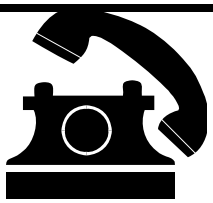
Direct-to-consumer advertising (DTCA) is the promotion of prescription drugs directly to the consumer via newspaper, magazine, television and internet marketing. DTCA for medications is commonplace in the U.S. In 1997 the FDA changed its policy to permit television advertising for prescription drugs. Much research and debate occurred regarding the appropriateness of this marketing and the US remains only one of two developed nations that permit this type of advertising. Relatively new to the scene is the direct-to-consumer marketing of cancer genetic testing. Currently, research is underway to determine the benefit and risk of this type of advertising.

Researchers at the University of Colorado attempted to assess the impact of direct-to-consumer marketing for genetic testing among women at varying genetic risk for breast and ovarian cancer. The study found that women were misinformed about the appropriateness of testing, meaning even when women were at low risk for a mutation, they believed they should consider testing. In addition, women in all risk groups overstated the benefits of genetic testing.

Genetic testing provides only one piece of information about a person's cancer risk—other genetic and environmental factors, lifestyle choices, and family medical history also affect a person's risk of developing cancer and other disorders. These factors are discussed during a consultation with a doctor or genetic counselor, but in many cases are not addressed by at-home genetic tests.

To help locate a genetic counselor in your area you can search the National Society of Genetic Counselors website at:
www.nsgc.org

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.

To update your record please contact:

Betty May, MS, CCRP
Project Coordinator

1-877-880-6188 (toll-free) or 410-502-9232

We're on the web!!!
http://hedwig.mgh.harvard.edu/cgn

For more information:

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

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

Cancer Information Service: http://cis.nci.nih.gov/

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

American Cancer Society: http://www.cancer.org

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