

News from the Cancer Genetics Network

Greeting from the Mid-Atlantic Cancer Genetics Network (MACGN)

We are proud to be entering our 7th year! Thank YOU for your continued participation! The MACGN continues to serve as a resource for new studies. Your participation has allowed researchers to look for new genes that may be related to colon cancer that runs in families, to find better screening tools for ovarian cancer, to find better ways for health care providers to communicate with their patients about their risk for cancer, and to determine ways to increase the quality of life among cancer survivors.

What now? We are hopeful that the MACGN will continue for at least another 5 years. We would like to keep in contact with you once a year, as we have in the past, to update your information. Thanks to all of you, we have had great success keeping our registry up-to-date.

The value of our registry increases with time. We appreciate your participation and your willingness to help us in the fight against cancer. Best wishes to you and your family.

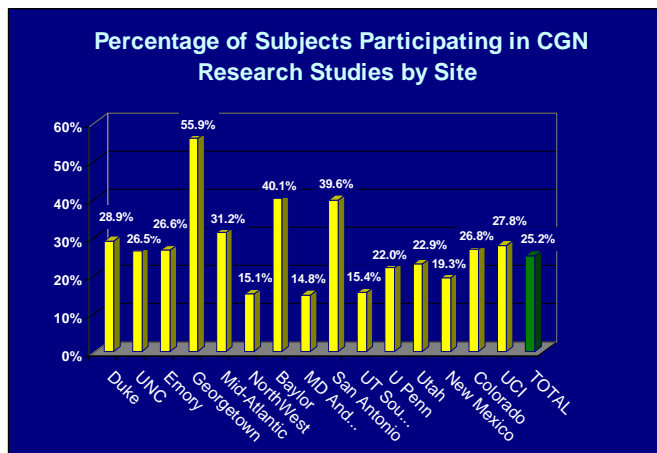
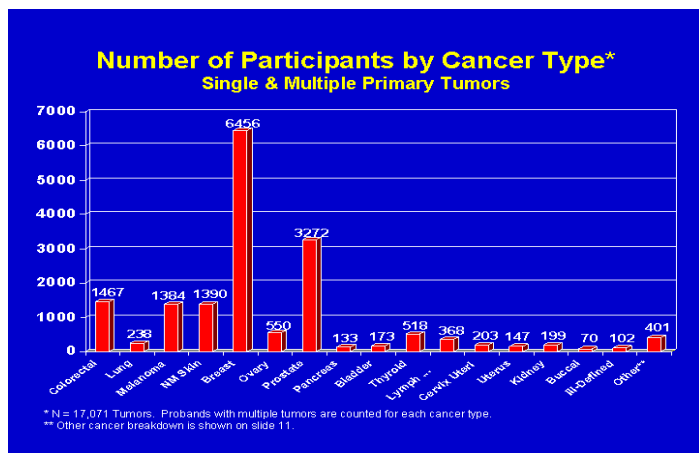
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Update on the Cancer Genetics Network (CGN)

Since CGN began in 1999, eight centers across the U.S. have worked together to recruit over **23,000** participants for this important research effort aimed at understanding the factors that contribute to cancer in families and improve cancer screening practices. This national collaboration makes possible research that a single institution could not carry out alone.

The graph below (left) shows the different types of cancer reported among our CGN participants. Breast and prostate cancers are the most commonly reported types. The graph on the right shows that over 25% of our CGN participants have enrolled and taken part in one or more research study offered by our national network of CGN sites.

About 9,000 of our participants have not had a personal diagnosis of cancer. Their participation in the CGN stems from the experiences of family members and their concern for the future of cancer research.



Research Study Update

Breast Screening Study

Through a collaborative effort between the CGN and the International Breast MRI Consortium, 195 women, including 13 from MACGN, were enrolled in a prospective study of screening mammography, MRI, and ultrasound. Participants were asymptomatic women 25 years of age and older who were at high risk for developing hereditary breast cancer. A total of six cancers were diagnosed, with MRI detecting all six cancers, while mammography detected two and ultrasound detected one cancer. These results have been presented at the annual meeting of the American Society of Clinical Oncology and have been submitted for publication.

Ovarian Cancer Screening Study

More than 2200 subjects at high risk for ovarian cancer have enrolled in this pilot study during the last five years. 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 providing more effective treatment of ovarian cancer and improving survival. Over the course of the study, 177 women participated from the MACGN registry. Currently we are awaiting approval of a five-year NCI funding for continuation of this project.

Colon Cancer Sibpair Study

The CGN, through funding from the NCI, recently completed a pilot study of genes in brothers and sisters who have colon cancer. The goal of the study was to identify colon cancer genes by studying the variation of DNA sequences (genes) in affected sibling pairs. Researchers will also examine links between colon cancer and influences such as lifestyle habits and environmental factors. To date, 274 individuals have participated in this study including 47 from MACGN. We have identified regions in the genes that are shared more often by those with colon cancer. There is still much work to be done because there are 40 genes in this genetic region that will need to be studied.

Prostate Gene Discovery Study

This study was funded by the NCI and was conducted at seven institutions nationwide. The goal of this study was to characterize and obtain biological specimens from individuals with early onset prostate cancer (age at diagnosis of less than 65 years) and their family members, as well as a series of high-risk families. Enrollment to this study has closed and data analysis is in progress. Nationwide recruitment efforts have been impressive, with 1,011 prostate cancer cases and 369 family members enrolled. Biospecimens from 1,167 individuals have been obtained, including 125 men from the Mid-Atlantic region. Focus will now be on identifying the prostate cancer susceptibility genes and their possible interactions with lifestyle and environmental risk factors.

THANKS TO ALL OF YOU WHO HAVE PARTICIPATED IN OUR RESEARCH!

GEMS (Genetic and Environmental Modifiers Study)

Researchers at Duke University have launched this study to find environmental and genetic factors that influence the risk of getting breast cancer in women who have mutations in the BRCA1 and/or BRCA2 genes. An alteration in these genes increases the chance of developing breast cancer and ovarian cancer. In the future, such research may lead to tailored screening and treatment programs based on a deeper understanding of breast cancer genetics. So far, 41 women have participated from the Mid-Atlantic area. If you have had a diagnosis of breast cancer within the last three (3) years and have had genetic testing for the BRCA 1/2 genes with either positive or negative results, you may be eligible for this study.

Know your family history

Health information about you and your relatives is called

your family medical history. Family members share genes and often have similar environments, lifestyles, and habits. Even though you cannot change your genetic makeup, you can change your behaviors. Most common human diseases result from interaction of genes with environmental and behavioral factors that CAN be changed by exercising, eating right and quitting smoking. If you know your family history, then you and your health care provider can discuss how to lower your risk for disease.

Although most Americans understand that their family health history is important to their own health, only one-third of us actively collect this information. To help with this, the U.S. Department of Health and Human Services has released a new, free computer program that organizes important health information that you can share with your health care provider. This program is called, "My Family Health Portrait," and can be downloaded at:

<http://www.hhs.gov/familyhistory/>.

We encourage you to take some time at your next family gathering to discuss your family history. It may not be the most comfortable subject, but it may provide information to help you decrease your risk for cancer and many other common diseases, and **that** is definitely comforting.

Stay in Touch!

Keep us informed of any changes in your information including



newly diagnosed medical conditions, a new cancer diagnosis in yourself or a family member, deaths in your family, and change of address or contact information.

Remember, it is important to respond to our annual mailings even if there are no changes.

With your help, and by keeping our records current, our registry will continue to be a valuable resource for cancer research.

If you have any questions, please contact:

Betty May

**Johns Hopkins University, Baltimore
1-877-880-6188 (toll-free) or (410)502-9232**