



Over the last 5 years, Zeta Phi Beta Sorority Inc. National Educational Foundation has been a

leader in disseminating information about the Human Genome Project.

It now extends that leadership to facilitate community involvement in a new cancer genetics initiative with the Mid Atlantic Cancer Genetics Network, Johns Hopkins University.

We invite you to join  
**Zeta Phi Beta Sorority, Inc.**  
**National Educational Foundation**  
 and  
**the Cancer Genetics Network**  
 to help answer some of these  
 and other important questions:

- Why does cancer run in some families?**
- Why do some people with inherited genetic changes develop cancer and others do not?**
- How does lifestyle or environmental factors interact with genes to cause or prevent cancer?**
- How can we use this new knowledge to prevent cancer?**
- How can individuals and families cope better with cancer and cancer risk?**

**Zeta Phi Beta Sorority, Inc.**

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**National Educational Foundation**

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**For More Information, Contact:  
 Mid Atlantic Cancer Genetics Network**

The Johns Hopkins University  
 2024 E Monument Street, Suite 2-606  
 Baltimore, MD 21205-2223  
<http://www.MACGN.org>  
 1-877-880-6188  
<http://epi.grants.cancer.gov/CGN/>



**Zeta Phi Beta Sorority, Inc.**  
**NATIONAL EDUCATIONAL  
 FOUNDATION**



Funded by the National Cancer Institute,  
 the National Institutes for Health



# Cancer Genetics Initiative

Helping communities,  
 families and doctors  
 learn more about  
 genes and cancer

Zeta Phi Beta Sorority, Inc.  
 National Educational Foundation  
 Mid-Atlantic Cancer Genetics Network

## Zeta Phi Beta Sorority, Inc. National Educational Foundation

The National Educational Foundation (NEF) feels strongly that all minority communities should be informed about our country's exploration into genomic research.

In 1997, NEF determined that there was a need for basic information about the Human Genome Research Program at the National Institutes of Health. At that time, NEF affirmed the need for a mechanism to engage the minority and genetics communities in discussions about the ethical, legal, and social issues surrounding genomic research. In 1998, the Foundation established a Sorority-wide initiative, the Human Genome Project. This project provides up-to-date genomic information to minority communities. NEF is particularly suited to do this given its representation and affiliations on an international level with over 100,000 Zeta memberships. NEF-sponsored Human Genome Project Conferences have been presented in urban, suburban and rural communities across this country and abroad.

Even though a large share of both private and public research dollars is being devoted to genomic research, the level of awareness about genomic research among minority communities remains low. Moreover, the lack of involvement of significant numbers of minorities in genetic research and related sciences, illustrates the need for engaging minority students in careers in science and medicine.

Genetic research provides information on some of the most serious diseases that affect all populations but in particular those that affect minority communities (i.e. Tay Sacks disease, prostate cancer, sickle cell anemia). **Because genomic research has the potential to provide individualized preventive medicine that can improve human health, it is essential that minorities take the opportunity to participate in research studies.** Without such participation it may be difficult for minorities to gain access to individualized therapies that will prevent diseases such as cancer.

## The Mid Atlantic Cancer Genetics Network (MACGN)

MACGN is one of eight U.S. academic members\* of the Cancer Genetics Network (CGN). Funded by the National Cancer Institute (NCI), all 8 have joined forces to build on our knowledge of cancer genetics by:

- Supporting studies about the genetic basis of cancer susceptibility.
- Exploring ways to integrate this new knowledge into medical care.
- Identifying ways to ameliorate associated psychosocial, ethical, legal, and public health issues.

Together, the centers make it possible to do research that a single institution may not be able to accomplish because of insufficient numbers of participants, or the time needed to recruit them.

Personnel involved with CGN include doctors, genetic counselors, researchers, health educators, nurses and data specialists.

CGN invites women and men **to join** who have a personal or family history of cancer, and who may be interested in participating in studies about inherited susceptibility to cancer. More than 20,000 individuals have enrolled in this unique program.

For more information or to join, contact:  
Mid Atlantic Cancer Genetics Network  
<http://www.MACGN.org>  
1-877-880-6188

\*Collaborating Scientific Centers  
Carolina-Georgia Center of the Cancer Genetics Network  
Lombardi Cancer Center Cancer Genetics Network  
Mid-Atlantic Cancer Genetics Network  
Northwest Cancer Genetics Network  
Rocky Mountain Cancer Genetics Coalition  
Texas Cancer Genetics Consortium  
UCI-UCSD Cancer Genetics Network Center  
University of Pennsylvania Cancer Genetics Network

## The Cancer Genetics Network Registry

**As a part of this initiative you will receive information about:**

- Developments in cancer and genetics research.
- Activities of the Registry.
- Benefits of being a part of the Registry.
- How to make informed decisions about joining the Registry.
- Opportunities and procedures for joining research studies.

As a member of the registry you have an opportunity to learn about new studies and, if you are eligible, to choose to be in one. It does not mean that you have to take part in any research study.

To join, you must have a personal or family history of cancer and fill out a questionnaire about your cancer history and that of blood relatives. If you are eligible for studies, CGN personnel will contact you to provide details of the study and answer questions.

### **Benefits**

Access to the latest information about cancer genetics.

Referral to cancer genetics specialists throughout the United States if you need assistance or advice.

Opportunities to participate in research studies for which you are eligible.

### **Joining this national registry is confidential and free**

Keeping your information private is essential. Participation in the CGN and any personal information you provide is strictly confidential, as required by law.

Your name will never be used without your permission and you can withdraw any time.

This study has Human Subjects approval from an accredited Institutional Review Board. Representation on these review boards includes leaders in the African American community.