Messenger

Newsletter of the Multi-Ethnic Study of Atherosclerosis

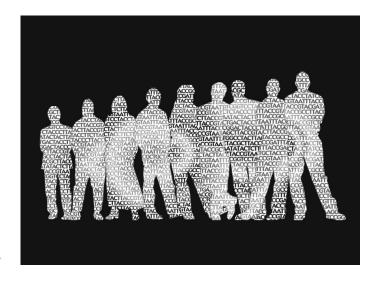
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New Opportunities for Genetics Research in MESA!

Thank you for your continued participation in MESA! We are sending out this special newsletter to let you know that MESA has joined a larger scientific group called "SHARe" Here are some important things to know about MESA's partnership with SHARe:

• The goal of SHARe is to identify changes in DNA that are related to heart disease. It is a genetic study that is very similar to other genetic studies we have told you about in MESA, except that SHARe uses newer technology to examine genetic data in more detail than we could in the past.



- Protecting your privacy and keeping your health and genetic data confidential is MESA's highest priority.
- If you have agreed to be part of other MESA genetic studies such as the MESA Family Study, your data will also be included in the SHARe project.
- If you indicated at a prior MESA visit that we could use your DNA for genetic studies, then your data will be included in the SHARe project. If you joined the MESA Family Study, then your data will also be included in the SHARe project.
- If you indicated at a prior MESA visit that you did NOT want your DNA used for genetic studies, then your data will NOT be included in the SHARe project.
- If, for any reason, you want to change your preference for the use of your DNA for genetic studies like SHARe, or if you have any questions that aren't answered below, please contact your field center using the phone numbers at the end of this newsletter.

You can read more about SHARe in the following pages. The continued success of MESA depends entirely on you and your participation with our efforts. Ultimately, our work together will allow doctors to provide better care to their patients and help health professionals lessen the prevalence of dangerous diseases. On behalf of all of the MESA staff and researchers, we thank you and say: We couldn't do it without you!

Genetics and MESA

We are excited to let you know that MESA is now participating in SHARe! SHARe stands for SNP Health Association Resource. As a participant in MESA, if you have consented to genetics research, you will be joining thousands of individuals from other research studies to help scientists understand the link between genes and conditions such as heart disease, high blood pressure, and stroke.

We've previously discussed some new opportunities for genetics research that will involve MESA (refer to the summer 2008 MESA Messenger available at

http://www.mesa-nhlbi.org/ParticipantWebsite/ParticipantNews.aspx). Now we want to give you an update on this work, starting with a little background information on genes and DNA.

What's in your genes?

Inside the cells in your body is an instruction booklet made up of bundles of long, winding DNA. The complete set of this DNA is known as a genome and it consists of over three billion individual DNA building blocks or letters (nucleotides). This is the equivalent of 200 phone books (with 1,000 pages each) worth of information in each of your cells!

The DNA "letters" spell out specific instructions in the form of genes. The completion of the Human Genome Project in 2003 revealed that humans have about 20,000 to 25,000 genes.

Genes help determine your eye color and hair color, and they also can determine what diseases you may (or may not) get. For example, does high blood pressure or kidney stones seem to run in your family? Many conditions such as these have a genetic component, and an increased risk of getting them may be passed on from a parent to a child.

The SHARe Project

To better understand the role that our genes can play in causing or preventing heart disease and other disorders, researchers are examining DNA to look for "spelling" differences that might be linked to a disease. To do this, researchers need to examine the DNA of thousands of people, and then compare genetic spellings with the occurrence of diseases or with measurements that may indicate a disease

(such as high blood sugar, which may indicate diabetes).

This is a very large and complex undertaking and in order to carry it out the National Heart, Lung, and Blood Institute (NHLBI), which funds MESA, has created a project known as SHARe.

Your involvement in SHARe as a MESA participant is important for several reasons. MESA is one of the few large research studies that is looking at early measures of cardiovascular disease such as calcium in the arteries, heart size, and artery thickness. In addition, MESA includes participants from diverse racial and ethnic groups and genetic backgrounds.

These data may help researchers develop better ways to prevent, diagnose, and treat diseases, as well as determine whether to tailor prevention and treatments to specific populations, or even to specific individuals. This could lead to more effective treatments and reduce the likelihood of side effects.

Genes, SNPs and GWAS

As noted, SHARe stands for SNP Health Association Resource. SNP (pronounced "snip") is an abbreviation for single nucleotide polymorphism. This is a variation in one of the building blocks ("letters") in your DNA. SNPs are very common, and occur in about one every 1,000 letters along your DNA.

For the MESA SHARe project, researchers will look at 1 million of these SNPs, or genetic variants, in each study participant who has agreed to have their DNA analyzed. Using computer programs, researchers will compare the genetic spellings with many of the measurements that have been made in participants during their clinic visits.

Examples of conditions currently being studied by this technique include asthma, Alzheimer's disease, many types of cancer, diabetes, heart disease, heart failure, obesity, osteoarthritis, and stroke.

Researchers will also utilize the information to better understand how genetic differences interact with lifestyle and environment (including factors like eating behavior, cigarette smoking, physical activity level, and exposure to air pollution) to increase or decrease a person's likelihood of getting a disease.

Questions about the SHARe Study

We realize you may have many questions about this study. If you would like more information, please call the numbers listed at the end of the newsletter.

Am I included in the SHARe study?

Only participants who consented to genetic research during one of their MESA clinic visits are included in MESA SHARe.

If you did not specifically consent to participate in genetics activities, you will not be genotyped and your data will not be used for genetics-related activities. If you do not remember if you agreed or want to change your consent, please contact your Field Center. The phone number is at the end of this article.



Can these genetic studies be used to identify me?

Protecting your privacy is one of our highest priorities in MESA. Your genetic information alone cannot be used to identify you. You can only be identified if your genetic information is directly connected to your personal information (such as your name, address, social security number, place of birth or other personal identifiers). In order to prevent this from happening, the genetic information collected in the MESA study is stored completely separately from your personal information. We remove all personal information from the genetic data so the data cannot be linked with any participant.

Genetic information is stored in a database at the National Institutes of Health (NIH) National Center for Biotechnology Information (NCBI, http://www.ncbi.nlm.nih.gov) under extremely secure conditions. While this database serves as a central repository for scientists to study the relationship between genetic information and diseases, only authorized investigators who meet strict requirements can access the information, and researchers are prohibited from sharing the data or trying to determine the identity of the participants.

We are very careful about who is allowed access to the MESA data files. We train and certify all staff in the protection of participants' privacy and confidentiality and require all MESA researchers to have approval from their Ethics Review Board. These extensive precautions make it highly unlikely that anyone could identify a specific person from the genetic information collected in MESA.

What will MESA investigators tell me about my DNA?

SHARe is an early step in the process of understanding the genetic basis of common diseases. The scientific results from MESA-SHARe are not like the results for individual genetic tests that you might get from your doctor, such as testing for specific genes that influence breast cancer or Alzheimer's disease. Instead, we will be studying whether spelling differences in DNA across thousands of MESA participants relate to characteristics such as high levels of cholesterol or high blood pressure, or to diseases like heart attack and stroke.

Results from SHARe will help researchers identify genes for additional study to see if they may be important for health. Because SHARe is for research purposes only and findings will need to be explored further to understand their importance, we will not provide you with any information from MESA-SHARe about your own specific genetic makeup.

This is a very exciting time for the field of genetics research and we are delighted that MESA will be playing a role. (?)

Glossary of Terms You May Hear

Deoxyribonucleic Acid or "DNA": The chemical inside your cells that contains the genetic instructions for making living organisms. DNA is often compared to a set of blueprints or a code since it contains the instructions needed to construct other components of cells.

Genome: The complete set of genetic information (DNA) in a cell or living organism which consists of over three billion individual DNA building blocks or letters.

Single Nucleotide Polymorphisms or "SNPs": (pronounced "snips") Small variations or spelling differences in DNA. They are very common, occurring at a frequency of about one every 1,000 DNA letters.

National Institutes of Health or "NIH": The agency of the United States Department of Health and Human Services that is responsible for conducting and supporting medical research. It consists of 27 institutes and centers and provides leadership and financial support to researchers in every state and throughout the world.

National Heart, Lung, and Blood Institute or "NHLBI": Part of the National Institutes of Health, the NHLBI plans, conducts, and supports research related to the causes, prevention, diagnosis, and treatment of heart, blood vessel, lung, and blood diseases; and sleep disorders. The Institute also administers national health education campaigns on women and heart disease, healthy weight for children, and other topics. The MESA study is funded by the NHLBI.

National Center for Biotechnology Information or "NCBI": Part of the National Institutes of Health, this national resource for molecular biology information includes the databases in which MESA SHARe data are stored.

SNP Health Association Resource or "SHARe": A web-based set of data from a number of large studies including MESA, the Framingham Heart Study, and the Women's Health Initiative. The data are available to qualified researchers to study the link between genetic information and health in order to advance the understanding of the causes and prevention of heart disease and other disorders.

Thank You!

We hope this newsletter has helped you learn more about the MESA SHARe project and given you a better understanding of the importance of the research in which you graciously participate. If you have any questions about the information in this newsletter, or about genetics research in MESA, please contact your local field center. They would love to hear from you!

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