The Jackson Heart Study (JHS)

is investigating why heart disease is more common and more deadly for African Americans by seeking to find out how lifestyle habits, medical history, social and cultural influences, stress, and genetic factors relate to heart disease. The study of genetic factors involves the examination of genetic material (DNA) in blood cells to identify variations in genes that may increase risk or provide protection from heart disease, high blood pressure, and stroke. Genes are inherited units of information inside our cells that contain the instructions for our growth and development. Although the specific type of genetic research will vary, there are three basic types of studies that can show associations between genes and disease development. These are:

- Candidate gene studies which test differences in genes that the scientist believes are involved in the disease development.
- Genome-wide association studies compare all of the DNA in people with an illness to the DNA of people without the illness. For example, they would test to see if persons with hypertension and persons without hypertension have differences in a certain area of the genetic material.

Admixture mapping association studies are specific for populations with mixed ancestry, like African Americans, who descended from Africans, Europeans, and/or Native Americans. Differences in ancestry can now be identified in the DNA and are useful for examining racial and ethnic differences in risk for heart disease.

What does genetics have to do with health?

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- Family history of disease is among the first questions asked during doctor visits because virtually all illnesses arise from the combined effects of genes, environment, and lifestyle.
- Changes within your genes may protect you from certain diseases or put you at greater risk.
- Some illnesses like sickle cell disease and cystic fibrosis result primarily from genes.
- More common conditions such as diabetes, heart disease, and cancer also involve genes, but are usually greatly influenced by environment and/or lifestyle as well.
- Genetics is beginning to play a more

important role in health care and disease prevention. Once individuals are familiar with their disease risks, including genetic risks, it is possible to prevent or detect heart disease early enough to reduce death and disability.

What does participation in the JHS genetic studies involve?

- If you consent to participate in the genetic studies, blood samples for these studies will be drawn at the same time that blood for other studies is drawn.
- With your permission (consent),
 - DNA will be separated from your blood and preserved for future genetic studies and;
 - Some of your blood cells will be frozen by a special method (cryopreservation) that produces a living tissue sample to provide an unlimited supply of DNA.

Your DNA blood samples, along with other blood samples and any data generated from your exam participation, will be released only to researchers as indicated on your consent form and only for the types of studies you select.

 It is important that we find answers to the health problems of African Americans as quickly as possible so we can begin to address these problems. To allow this, we are asking your permission to share your genetic information and the results of the other tests done by the JHS with many qualified scientists from around the world. We will only do this with your permission, and will not reveal your identity to anyone outside the JHS.

What are some of the benefits of

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participating in the JHS genetic studies?

- The JHS genetic studies seek to identify genetic risk factors that may contribute to diseases common in African Americans.
- The studies will help to determine how these genetic factors lead to disease, and what can be done to prevent or treat these diseases.
- As more is learned about the genetics of African Americans, new and more effective therapies for African Americans can be developed.
- Heart disease, high blood pressure, and stroke occur in virtually all populations. Therefore, the genetic studies are likely to help not only African Americans, but all people.

What are some of the risks related to genetic studies and how is the JHS protecting participants from the possible risks?

In genetics research, it is possible to find genetic factors that may give other information about a participant's future health. Insurance companies or employers sometimes ask about individuals' genetic or family history information. The Jackson Heart Study would never give any information about you to anyone (including family members) without your permission to share genetic data with other researchers; all identifying information will be removed so that your identity is protected. No data will be shared until we have put in place the security measures necessary for ensuring this confidentiality. Some people are concerned about being cloned by researchers or researchers making changes to their DNA. The JHS is not doing this and will **not** permit other researchers to use your blood samples for such purposes.

Please feel free to call the telephone number on this brochure to ask any questions you may have about the JHS genetic studies.



A Jackson Heart Study Family

The Jackson Heart Study is sponsored by:

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JACKSON HEART STUDY

