The Hispanic Community Health Study/Study of Latinos and Genetic Research

The human body is made up of cells that contain genetic substances. Genes are found in the cells and are made up of deoxyribonucleic acid (DNA), the unique genetic material that carries the instructions for the body’s development and function. Half of a person’s DNA is inherited from their father and the other half is from their mother. Every human shares 99% of the same DNA, all the differences we see among people lies in the remaining 1%. Ribonucleic acid (RNA) is a copy of DNA which plays an important role in the way genes work. Genes are important because they are what determine a person’s characteristics. Genetic researchers study both DNA and RNA to understand more about genes because these play an important role in a person’s health.

Why is genetic research important?
Genetic researchers try to find out what genes may relate to certain diseases. Early research focused on understanding certain birth defects and genetic variation, for example sickle cell anemia. However, often times carrying a particular gene does not automatically mean that a person will be affected by the disease associated with that gene. Most health problems are caused by a combination of factors rather than just genetics. In recent years, genetic research has helped us to understand how genes and the environment play a role in diseases such as cancer, diabetes, and cardiovascular disease. The understanding of how each gene works and what it does can also lead to identify genetic and environmental causes of common illnesses like asthma, arthritis, and the development of many types of dementia (for example, Alzheimer’s disease). Understanding more about diseases caused by genes can lead to earlier diagnoses, interventions, and can improve treatment options for patients.

How is HCHS/SOL using participants’ genetic materials?
During the HCHS/SOL visit 1, many participants gave consent to provide their DNA and RNA for current and future genetic research. The DNA and RNA are being examined in order to learn how genes and gene products contribute to the function of the brain, lungs and other organs as well as to the risk of diseases such as heart disease, stroke and diabetes. The genetic studies performed for HCHS/SOL may not be able to tell us whether an individual participant will get diseases or not, nor are they intended to diagnose any health conditions at this point in time. However, findings related to genetic materials in HCHS/SOL may benefit future generations and humanity in general.

What is the Genetic Information Nondiscrimination Act of 2008 (GINA)?
Many people are afraid of being discriminated against or treated unfairly due to differences in their DNA that may increase their chances of developing a disease. The Genetic Information Nondiscrimination Act (GINA) is a federal law passed in 2008. This law makes it illegal for health care insurance providers and employers to discriminate against people due to any differences in their genes. GINA is an important law that protects people who may benefit from genetic testing and/or participating in genetic research but are afraid of being treated unfairly. Hispanic/Latino participation in genetic research studies is important because there is a low representation of this group in genetic studies. Participation in research studies, such as HCHS/SOL, may provide important information that can help us understand the health of the Hispanic/Latino population in the United States.

For more information regarding genetics and genetic research, please visit the following websites:
* National Human Genome Research Institute – Frequently Asked Questions About Genetic Testing at: https://www.genome.gov/19516567/
* National Institutes of Health – All of Us Research Program – Participation: https://www.nih.gov/allofus-research-program/participation