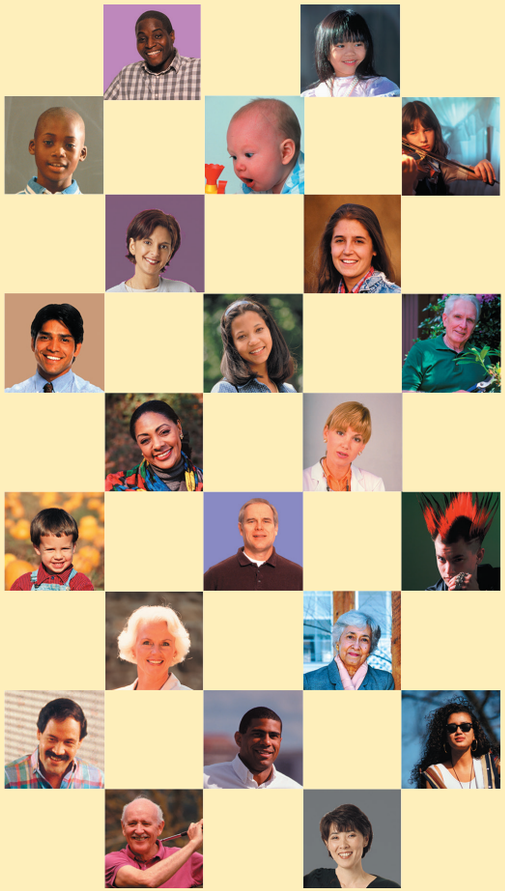
Thank you

Your generous gift of tissues and clinical information to the GTEx project makes possible research that will help improve our understanding of common diseases, giving hope that we will find better ways to prevent, diagnose, treat, and cure these diseases in the future.



You can find more information about the GTEx project at:
http://genome.gov/GTEx

Supported by the Common Fund
Office of the Director
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US Department of
Health and Human Services

You & GTEx

Genotype-Tissue Expression Project

What is GTEx?

The Genotype-Tissue Expression project, or GTEx, is an important medical research study supported by the National Institutes of Health (NIH), one of the world's foremost medical research agencies. The goal of GTEx is to increase the understanding of how changes in our genes contribute to common human diseases, in order to improve health care for future generations.

Genes are the packets of information in the cells of our bodies that parents pass along to their children. Genes determine traits such as eye color, height, and blood type. Previous research has shown that certain changes in genes can increase a person's risk of developing common diseases like cancer, heart disease, diabetes, and Alzheimer's disease. How changes in genes affect the risk of having these diseases, however, is poorly understood.

Why does GTEx need tissue and organ donations?

Because common human diseases often affect a wide variety of different organs and types of tissues, GTEx researchers need to examine samples of as many types of tissues and organs donated by as many people as possible.

Who can donate?

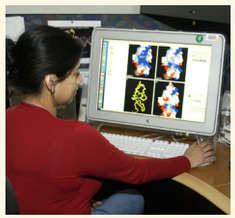
One group that can donate to the GTEx study is people who are having various kinds of surgery. If a surgery patient agrees ahead of time, tiny amounts of tissue removed during surgery, such as fat, skin, or muscle, can be donated for use in the GTEx project. Only tissue which needs to be removed for medical reasons can be donated to the GTEx project. Donating to the GTEx project will not cause any additional tissue to be removed.

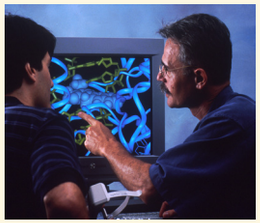
A second group that can donate is people who have agreed to donate organs (like kidneys, heart, and liver) or tissues (like bone and cornea) for use as medical transplants after they pass away. Donating to GTEx would not interfere with the use of the organ or tissues for transplantation, which takes priority. Compared to surgical donors, organ and tissue donors who have died can provide many more types of tissues for research studies.

The family of a deceased person also can donate their loved one's organs and tissues for transplantation, and can donate unneeded organs and tissues to benefit research studies like GTEx. Even people who do not qualify to donate organs or tissue for transplants may still be able to donate tissue to GTEx for research.

What happens to organs and tissues that are donated?

Tissues and portions of organs donated to GTEx are stored in a "biobank" that preserves them for studies now and in the future. These studies will detect changes in genes and learn how much each gene is active in different tissues and organs. The patterns of genetic changes, like a fingerprint, are unique to each person. To ensure that GTEx donor tissues can be shared with many scientists for years to come, some of the skin and blood cells are treated so they will remain alive for a very long time.





GTEx also stores clinical and genetic information about donors, such as their diseases, medications, and cause of death, after removing personal information that might allow others to identify the names of the donors. Scientists in academic, government, and commercial laboratories, worldwide, can ask to use the GTEx tissues and clinical and genetic information to help them study the role of genes in common diseases.

Are there risks associated with being a GTEx tissue or organ donor?

GTEx is careful to ensure that a donor's clinical and genetic information remains confidential. Despite taking these precautions, there is a small possibility that someone might connect the name of a donor, or a blood relative, to this information. State laws and a federal law, the Genetic Information Non-discrimination Act (GINA), have been passed to help protect people from unfair treatment because of their genetic information.

Participation as a GTEx donor is voluntary. At any time, you may withdraw your tissues and related clinical information or those of your family member who died, although information and tissue samples already distributed to researchers cannot be withdrawn.