

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.



&
GTEx

GENOTYPE-
TISSUE
EXPRESSION
PROJECT

SUPPORTED BY THE COMMON FUND
OFFICE OF THE DIRECTOR
NATIONAL INSTITUTES OF HEALTH
US DEPARTMENT OF
HEALTH AND HUMAN SERVICES



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

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 our understanding of human diseases that affect many people and to improve health care for future generations.

GTEX researchers are studying the effects of changes in genes. 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 surgical patient agrees ahead of time, tiny amounts of tissue not needed for a medical procedure or a patient's care, such as fat, skin, or muscle, can be donated for use in the GTEX project.

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 die. These donors can indicate whether any organs or tissues not needed for transplants may be used for research studies like GTEX. 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. There is a small possibility, however, that someone might manage to 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), help protect people from being treated unfairly 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.

