

Genetics and Ethical, Legal, and Social Issues

I'm worried that I may be harmed by sharing my genetic information. Are there any laws to protect me from genetic discrimination?

- Yes. While there are many issues to be concerned about, there are state and federal laws to protect you.
- **Utah Genetic Testing Privacy Act.** This law “prohibits employers from using private genetic information for hiring and promotion purposes.” It also “places restrictions on health insurers’ use of genetic information.” Private genetic information in this law refers to anything derived from an inherited gene(s) or from specific DNA markers, which was been obtained from a genetic test or analysis of a person’s DNA. The law doesn’t include protection based on information obtained through a family health history.
 - » The law is available at: <http://www.le.utah.gov/UtahCode/section.jsp?code=26-45>
- **Genetic Information Nondiscrimination Act (GINA).** This is a federal law that “prohibits health insurers from requesting or requiring genetic information of an individual or the individual’s family members, or using it for decisions regarding coverage, rates, or preexisting conditions.” The law also prohibits employers from “using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment.” GINA also protects you from discrimination based on information obtained through a family health history.
 - » The law is available at: <http://thomas.loc.gov/cgi-bin/bdquery/z?d110:HR00493:>
 - » For more information about GINA visit: <http://www.genome.gov/24519851>

Where can I find more information?

- Genetic Science Learning Center <http://learn.genetics.utah.edu>
- Human Genome Project www.genomics.energy.gov
- National Human Genome Research Institute www.genome.gov
- The Library of Congress <http://thomas.loc.gov>
- Utah State Legislature www.le.utah.gov/

Sources

Utah Department of Health Chronic Disease Genomics Program
Department of Health and Human Services, The Genetic Information Nondiscrimination Act of 2008 Information for Researchers and Health Care Providers