

## Genetic Information Non-discrimination Act (GINA) Federal Law regarding Health Insurance Discrimination

GINA is a Federal law that prohibits discrimination in health coverage and employment based on genetic information. GINA, together with already existing nondiscrimination provisions of the Health Insurance Portability and Accountability Act (HIPAA), generally prohibits health insurers or health plan administrators from requesting or requiring genetic information of an individual or an individual's family members, or using such information for decisions regarding coverage, rates, or preexisting conditions. GINA also prohibits employers from using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment. Once GINA takes effect, it generally will prohibit discrimination based on genetic information in connection with health coverage and employment, no matter when the information was collected.

GINA defines *genetic information* as information about:

- An individual's genetic tests (including genetic tests done as part of a research study);
- Genetic tests of an individual's family members (defined as dependents and up to and including 4th degree relatives);
- Genetic tests of any fetus of an individual or family member who is a pregnant woman, and genetic tests of any embryo legally held by an individual or family member utilizing assisted reproductive technology;
- The manifestation of a disease or disorder in an individual's family members (family history); or
- Any request for, or receipt of, genetic services or participation in clinical research that includes genetic services (genetic testing, counseling, or education) by an individual or an individual's family members.

GINA provides a baseline level of protection against genetic discrimination for all Americans. Many states (including Utah) already have laws that protect against genetic discrimination in health insurance and employment situations. However, the degree of protection they provide varies widely, and while most provisions are less protective than GINA, some are more protective. All entities that are subject to GINA must, at a minimum, comply with all applicable GINA requirements, and may also need to comply with more protective State laws.

GINA's provisions do not extend to life insurance, disability insurance, or long-term care insurance. For example, GINA does not make it illegal for a life insurance company to discriminate based on genetic information. In addition, GINA's provisions generally do not apply to employers with fewer than 15 employees. For health coverage provided by a health insurer to individuals, GINA does not prohibit the health insurer from determining eligibility or premium rates for an individual **based on the manifestation of a disease or disorder** in that individual. For employment-based health coverage provided by group health plans, GINA permits the overall premium rate for an employer to be increased because of the manifestation of a disease or disorder of an individual enrolled in the plan, but the manifested disease or disorder of one individual cannot be used as genetic information about other group members to further increase the premium. GINA also does not prohibit health insurers or health plan administrators from obtaining and using genetic test results in making payment determinations.

**Resource:** <http://www.ginahelp.org/>