

New law prohibits discrimination based on genetic testing and family history

Genetic testing (i.e., identifying the risks of inheriting disease) has been widely heralded as a major breakthrough in disease prevention. Yet its adoption has been slowed by privacy issues. Polls have shown that Americans have been concerned about the possibility that employers and health insurers may use their personal genetic information to discriminate against them. Fortunately, a new federal law specifically outlaws this form of discrimination, thereby protecting patients and their families.

The age of genetic healthcare is here, and its benefits are now being realized. Genetic tests can allow for earlier detection of illnesses, often before symptoms have surfaced. A person who learns about his or her relatives' medical histories can take steps to reduce the likelihood that he or she will develop disorders that run in the family. Genetic research holds the promise of better therapies to treat diseases and improvements to disease prevention strategies.

To encourage the use of genetic services, testing, and research, the Genetic Information Nondiscrimination Act (GINA) was passed by Congress and signed into law by President Bush in May, 2008. This law makes it illegal for health insurers and employers to discriminate against a person because of his or her genetic information. For the purposes of GINA, genetic information is defined as information about:

- a person's use of, or referral to, genetics services (including genetic counseling and testing);
- the presence of a disease in a relative (up to and including fourth degree family members);
- the genetic tests of a person's relative;
- participation of an individual or family member in research involving genetics.

Specifically, GINA prohibits health insurers from denying coverage or charging higher premiums to individuals based on genetic information. A health insurer cannot request or require that an individual undergo a genetic test, or make any policyholder-related decision on the basis of the test.

Employers also cannot use genetic information to make decisions about hiring or firing an individual. Genetic information cannot be used to discriminate against an employee regarding job assignments or promotion. Employers cannot request or require a genetic test, nor can they purchase the genetic information of an individual or his or her family.

GINA is officially intended to protect individuals against the potential misuse of medical information, while encouraging the use of genetic tests and family history information in health care. However, the legislation will also benefit humanity by creating an environment in which more people will participate in medical research, contributing to potential medical advances.

For more information about GINA and genetics issues, please visit www.GINAhelp.org.

This information is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.



Genomic Medicine Institute/NE50
9500 Euclid Avenue, Cleveland, OH 44195
www.clevelandclinic.org/genetics
Center for Personalized Genetic Healthcare
Appointments: 216.636.1768
Hearing Impaired (TTY) Assistance: 216.444.0261