



Laws regarding genetic discrimination

The Genetic Information Nondiscrimination Act (GINA) was signed into law on May 21, 2008 and became fully effective November 21, 2009. GINA prohibits discrimination by health insurance companies and employers based on “genetic information.” In this case, “genetic information” is defined as: your genetic test results; your relatives’ genetic test results (up to and including fourth degree relatives); and/or information about family history of any disease or disorder. Information about your participation in research that includes genetic testing, counseling, or education is also protected.

Before GINA, several states had laws in place to protect against employment and health insurance genetic discrimination. Some of these state laws are more protective, while others are less protective than GINA. With GINA, all states now have baseline Federal regulations that provide minimum protections for genetic information. If a State law is more protective than GINA, compliance with the more protective State laws is required in addition to GINA.

What health insurance protections does GINA provide?

Group and individual health insurers, including Medicare supplemental policies, may not use your genetic information to set eligibility, premium or contribution amounts. Under GINA, genetic information cannot be considered a pre-existing condition. Health insurers may not request or require that you take a genetic test.

What employment protections does GINA provide?

Employers may not use your genetic information to make decisions involving hiring, firing, job assignments, and promotions. Employers may not request, require, or purchase genetic information about you or your family members. There are some exceptions to this rule: for instance, people employed in law enforcement might be required to submit DNA samples prior to becoming involved with crime scene investigation. Employers with fewer than 15 employees are not required to abide by the employment protections set forth by GINA.

What doesn't GINA do?

GINA does not restrict healthcare providers from offering or providing information about a genetic test to patients; nor does it require insurance companies to pay for any particular medical tests or treatments. It is important to note, that GINA does not protect information related to "manifest disease." What this means is that if you have already been diagnosed with a disease or symptoms related to a genetic condition, GINA does not apply. For example, if you have a BRCA 1 mutation and have already been diagnosed with breast cancer, GINA will not protect you against discrimination based on your breast cancer diagnosis. However, under certain circumstances, the Health Insurance Portability and Accountability Act (HIPAA) and the Affordable Health Care Act may prohibit health insurers from using information about previously diagnosed conditions when determining insurance coverage. GINA does not apply to life, disability, or long-term care insurance.

The Department of Defense and Uniformed Services are bound by different laws and regulations than civilians. Therefore, GINA does not protect members of the United States Armed Services, many service members who receive care through TRICARE (although family members are covered), the Veteran's Administration, or the Indian Health Service.

Where to go for more information about GINA

Facing Our Risk of Cancer Empowered:
www.facingourrisk.org

National Society of Genetic Counselors:
www.nsgc.org

Genetic Alliance
www.geneticalliance.org/ginaresource

Genetics and Public Policy Center:
www.dnapolicy.org/gina/

National Human Genome Research Institute:
www.genome.gov/24519851

www.GINAHelp.org