Laws Prohibiting Genetic Discrimination

The Genetic Information Nondiscrimination Act (GINA) was signed into law in 2008 and was fully enacted on November 21, 2009.

Several states have laws that provide additional anti-discrimination protections. GINA is a federal law so all states have baseline protections for genetic information. If a state law is more protective than GINA, compliance with the more comprehensive law is required in addition to GINA.

GINA Health Insurance Protections

Under GINA, genetic information cannot be considered a pre-existing condition. Group and individual health insurers, including Medicare supplemental policies, those regulated by the federal government under ERISA, state-regulated plans and Medigap may not use your genetic information to set eligibility, premium or contribution amounts. Health insurers may not request or require you to have genetic testing.

GINA Employment Protections

Employers may not use genetic information to make decisions involving hiring, firing, job assignments or promotions. Employers are not permitted to 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 before becoming involved with crime scene investigations. Employer-sponsored wellness programs are permitted to ask about medical or genetic information as part of a health risk assessment, as long as answering these questions is voluntary. Employers with fewer than 15 employees are not required to abide by the employment protections set forth by GINA.
GINA exceptions

GINA does not require health insurance companies to pay for health screenings, medical tests or treatments related to genetic test results. It is important to note that GINA does not protect information related to manifest disease; if you are diagnosed with a disease such as cancer or have symptoms related to a genetic condition, GINA may not apply. For example, if you have a BRCA1 mutation and have a breast cancer diagnosis, GINA will not protect you against discrimination based on your cancer diagnosis. However, laws such as the Health Insurance Portability and Accountability Act (HIPAA) and the Patient Protection and Affordable Care Act aim to safeguard the privacy of your medical information and prohibit health insurers from using this information for insurance coverage. GINA does not provide protection against discrimination in 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  
FacingOurRisk.org

GINAHelp.org

Genetic Alliance  
geneticalliance.org/gingaresource

National Human Genome Research Institute  
genome.gov/24519851

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FacingOurRisk.org