

The Genetic Information Nondiscrimination Act (GINA)



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In 2008, President George W. Bush signed the Genetic Information Nondiscrimination Act (GINA) into law. Under GINA, employers and health insurers can no longer discriminate against individuals based upon their genetic information. GINA protects Americans from genetic discrimination while encouraging each patient to seek out medical care that is specifically tailored to his or her genetic makeup.

Yesterday

- Health insurers and employers could discriminate against individuals based upon their genetic information. For example, a health insurer might refuse coverage to a woman whose DNA increases her risk of breast cancer.
- Because every person has dozens of DNA differences that could affect his or her chance of getting a disease, everyone needed to be concerned about genetic discrimination. DNA differences that increase a person's risk don't mean that he or she will develop a disease, but individuals might be targeted for discrimination based on the specific differences in their DNA.
- The development of genetic tests promised to give patients new power to create personalized ways of detecting, treating and preventing disease. But without protection from discrimination, patients were reluctant to undergo genetic testing.
- While some states had passed laws against genetic discrimination, the degree of protection from these laws varied widely among the different states. Many states had no law preventing genetic discrimination.

Today

- GINA protects individuals from discrimination by health insurers or employers based on genetic information.

- **Health Insurance** – Insurers may not discriminate against individuals based on family medical history or individuals' and family members' genetic tests and services.
 - Health insurers may not use genetic information to make eligibility, coverage, underwriting, or premium-setting decisions.
 - Health insurers may not request or require individuals or their family members to undergo genetic testing or to provide genetic information.
 - Insurers cannot use genetic information obtained intentionally or unintentionally in decisions about enrollment or coverage.
 - The use of genetic information as a preexisting condition is prohibited in both the Medicare supplemental policy and individual health insurance markets.
 - Narrow exceptions to the rules for health insurers are summarized online (<http://www.genome.gov/27535101>).
- **Employment** – GINA makes it illegal to discriminate against employees or applicants because of genetic information.
 - Employers may not discriminate on the basis of genetic information when it comes to any aspect of employment.
 - Whether by a supervisor, co-worker, client, or customer, harassment because of someone's genetic information is illegal.
 - It is illegal for an employer to fire, demote, harass, or otherwise "retaliate" against an applicant or employee who has filed a charge of discrimination, participates in a discrimination proceeding, or opposes genetic discrimination.
 - GINA makes it illegal for an employer to obtain genetic information, including family medical history, except under certain exceptions (<http://www.eeoc.gov/laws/types/genetic.cfm>).

- Employers are forbidden from disclosing genetic information about applicants or employees.
- GINA sets a minimum standard of protection that must be met across the country. It does not weaken the protections provided by any state law.
- The law does not cover life insurance, disability insurance, or long-term care insurance.

Tomorrow

- As genomic medicine is poised to revolutionize medicine, patients will be able to utilize advances in genetic testing to create highly personalized care and treatment plans without fear of discrimination.
- Patients may be more likely to participate in medical research that involves genetic testing because they no longer need to fear genetic discrimination.
- With more participants for vital medical research, doctors and scientists will be able to create new lifesaving treatments and cures based upon the underlying genetic causes of their patients' diseases.

More Information

Perspectives on Insurance Discrimination
(Journal of Clinical Oncology)

<http://jco.ascopubs.org/content/18/12/2484.full>

Cases of Genetic Discrimination
(National Human Genome Institute)

<http://www.genome.gov/12513976>

A Guide to the Genetic Information Nondiscrimination Act
(GINA)

(Genetic Alliance)

<http://www.geneticalliance.org/ginaresource>

The Genetic Information Nondiscrimination Act
Summary of the Law (thomas.gov)

<http://thomas.loc.gov/cgi-bin/bdquery/z?d110:HR00493:@@D&summ2=m&>

Full Text (thomas.gov)

http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110_cong_bills&docid=f:h493enr.txt.pdf

Background and GINA News

(Genetics and Public Policy Center)

http://www.dnapolicy.org/policy.issue.php?action=detail&issuebrief_id=37

Federal regulations pertaining to GINA:

Summary for Employers

(Equal Employment Opportunity Commission)

<http://www.eeoc.gov/laws/types/genetic.cfm>

Summary for Health Insurers

(National Human Genome Institute)

<http://www.genome.gov/27535101>

Full text of these regulations:

(Regulations.gov)

Health Insurers

<http://www.regulations.gov/search/Regs/home.html#documentDetail?R=0900006480a3d8eb>

Employers

<http://www.regulations.gov/search/Regs/home.html#documentDetail?R=0900006480a64a2f>

Frequently Asked Questions

(Department of Labor)

<http://www.dol.gov/ebsa/faqs/faq-GINA.html>

Other Federal Anti-Discrimination Laws and How They Apply to Genetics

(National Human Genome Institute)

<http://www.genome.gov/12513979>

State Genetics Laws

(National Conference of State Legislatures)

<http://www.ncsl.org/programs/health/genetics/charts.htm>

For additional information contact:

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National Human Genome Research Institute (NHGRI)

<http://www.genome.gov/>