

Genetics and Federal Law

What is genetic discrimination?

Genetic discrimination occurs when an individual is treated differently than others because of his or her hereditary predisposition¹ to a particular disease. For example, an employer deciding not to hire a particular applicant because he or she is known to have a genetic predisposition to diabetes, alcoholism, or cancer would be considered an instance of genetic discrimination.

Why should you care about genetic discrimination?

The potential for employers and insurance companies to discriminate based on a person's genetic characteristics creates fear in individuals that their genetic characteristics may be used against them when applying for jobs or for insurance. This fear may then push some individuals to decide not to disclose information to healthcare professionals and decline early screening and preventative measures, which may be important for their health and medical care.

Are there any federal laws that protect people from genetic discrimination?

Yes, federal law protects against genetic discrimination in some contexts. Below is a brief summary of some of the federal laws that cover genetic discrimination in the areas of employment and insurance.

I. EMPLOYMENT

A. **GINA (Genetic Information Nondiscrimination Act) – Employment provisions**

GINA prohibits employers, including employment agencies, labor organizations, and joint labor-management committees, from discriminating against an employee based on his or her genetic information. GINA defines genetic information as information about an "individual's genetic tests, the genetic tests of family members of such individual, and the manifestation of a disease or disorder in family members of such individual."² The law protects against the use of genetic information in all employment practices, including hiring, firing, job application, job assignment, training, and promotions. Additionally, employers cannot request, require, or purchase an employee's genetic information except in limited circumstances. For example, an employer may obtain an employee's genetic information when it offers health or genetic services as part of an *optional* wellness program.³ However, if an employer comes to possess an individual's genetic information due to one

¹ A hereditary predisposition or a genetic predisposition (sometimes also called genetic susceptibility) is an increased likelihood of developing a particular disease based on a person's genetic makeup. *What does it mean to have a genetic predisposition to a disease?*, Genetics Home Reference (July 1, 2014), <http://ghr.nlm.nih.gov/handbook/mutationsanddisorders/predisposition>.

² 42 U.S.C. § 2000ff(4) (2008).

³ Wellness programs are programs intended to improve and promote health and fitness that are usually offered through the work place, although insurance plans can offer them directly to their enrollees. These programs allow your employer or plan to offer you premium discounts, cash rewards, gym memberships, and other incentives to participate. Some

of the exceptions; the employer must treat this information as confidential and must not disclose this information.

IMPORTANT: GINA's employment protections do not apply to employers with fewer than 15 employees, and its protections do not extend to the US military.

B. ADA (Americans with Disabilities Act)

The ADA prohibits discrimination in the workplace for a "qualified individual with a disability." The ADA does not definitively apply to individuals with a genetic predisposition; however, the Equal Employment Opportunity Commission (EEOC) has interpreted the ADA to prohibit workplace discrimination of healthy persons based on genetic status.

C. Executive Order #13145

In 2000, President Clinton signed an Executive Order that prohibits the federal government from using genetic information in hiring or promotion decisions for federal employees.

Where can I report a violation of GINA or the ADA?

If you believe you have been discriminated against at work you can file a claim with the Equal Employment Opportunity Commission (EEOC).

For information on filing a claim, please visit: <http://eeoc.gov/employees/charge.cfm>

For a description of how the EEOC handles each claim, please visit: <http://eeoc.gov/employees/process.cfm>

II. INSURANCE

A. GINA (Genetic Information Nondiscrimination Act) – Insurance provisions

In general, GINA prohibits group, individual, Medigap, and state government health plans and health insurance companies from using genetic information about an individual to adjust a group plan's premiums. Additionally, GINA prohibits individual plans from denying coverage, adjusting premiums, or imposing a pre-existing condition exclusion based on genetic information; from requesting, requiring, or purchasing genetic information for underwriting purposes or prior to enrollment; and from requiring or requesting genetic testing.⁴ Under GINA, genetic information includes genetic test results, family medical history, and the use of genetic services.

examples of wellness programs include programs to help you stop smoking, diabetes management programs, weight loss programs, and preventative health screenings. *Wellness Programs*, HealthCare.gov (June 24, 2014), <https://www.healthcare.gov/glossary/wellness-programs/>.

⁴ Amanda K. Sarata, James V. DeBergh, Jennifer Staman, *The Genetic Information Nondiscrimination Act of 2008 and the Patient Protection and Affordable Care Act of 2010: Overview and Legal Analysis of Potential Interactions 3* (Congressional Research Service 2011)

IMPORTANT: The insurance protections of GINA *do not apply* to life, long-term care, or disability insurance policies.

B. HIPAA (Health Insurance Portability and Accountability Act)

Before the passage of the Affordable Care Act, the provisions of HIPAA provided that genetic information could not be considered a pre-existing condition; however, HIPAA allowed group health plans to generally have exclusion periods based on pre-existing conditions. Although the insurance providers could not create these periods based only on genetic characteristics, they were allowed to in the presence of a diagnosis or manifestation of a genetic condition.¹ This is no longer the case, as the Affordable Care Act established that group health plans can only impose pre-existing condition exclusion periods until their plan year renews in 2014. In other words, group health plans can no longer have exclusion periods based on genetic characteristics that are manifested or not because group health plan exclusion periods themselves, as a whole, will no longer exist after 2014. It is important to note however, that HIPAA does not prevent a health plan from establishing limitations or restricting the amount, level, extent or nature of the benefits or coverage for similarly situated individuals enrolled in the plan, i.e., a plan can exclude coverage for a particular procedure for all individuals. For example, a plan can decide not to cover prophylactic mastectomies for all policy holders.

GINA clarifies and strengthens HIPAA nondiscrimination provisions with respect to genetic information and genetic testing.⁵ In other words, GINA amends the privacy regulations under HIPAA, and together these laws make genetic information considered confidential medical information; which in turn, prevents group, individual, Medigap, and state governmental health plans from using or disclosing the genetic information of an individual.

IMPORTANT: HIPAA applies to group health insurance companies, not private individual health plans

C. ACA (The Patient Protection and Affordable Care Act)

The Patient Protection and Affordable Care Act of 2010 created significant reforms to the private health insurance market across the nation.⁶ These reforms included changes that limit the ability of a group health plan or health insurance providers to set premiums or determine eligibility for coverage based on “health status factors,” which includes genetic information.⁷ In addition, the ACA explicitly prohibits group health plans and health insurance providers from denying coverage based on pre-existing conditions.

D. Possible Interactions Between GINA and the ACA

⁵ *Id* at 2.

⁶ Sarata, *supra*, at 1-7.

⁷ *Id* at 1.

While GINA expressly states that insurers may not use genetic information in determining health insurance premiums for individuals or groups, the ACA specifically defines the factors that health insurance providers may consider when deciding whether to provide coverage for an individual or adjusting premiums.⁸ These factors are: (1) whether an individual is seeking self or family enrollment in a plan or coverage; (2) rating area⁹; (3) age; and (4) tobacco use.¹⁰ No other factors may be considered by a health insurance provider when determining eligibility for coverage or premium rates; thus, since genetic information is not listed as one of the factors, insurers may not consider this information to determine eligibility or premium rates.

In conclusion, the ACA and GINA both have the goal of prohibiting genetic discrimination against individuals¹¹; both laws complement each other and decrease the likelihood of discrimination by prohibiting the consideration of genetic information in health insurance premium and eligibility determinations.¹²

E. GINA and Life, Long Term Care, and Disability Insurance

Unfortunately, the protections provided by GINA do not apply to life, long term care, or disability insurance. However, individual states may have enacted laws providing further regulations on the use of genetic information.

Genome.gov provides a summary of the current state of laws regarding genetics in individual states:¹³

At present, 48 states and the District of Columbia have passed laws preventing genetic discrimination in health insurance providers and 35 states and the District of Columbia prevent genetic discrimination in employment. GINA sets a floor of minimum protection against genetic discrimination and does not [over take] state laws with stricter protections. *[As of July 2014], 15 states have additional laws restricting the use of genetic information in determining coverage for life insurance, 17 states for disability insurance, and 9 states for long-term care insurance.*

Where can I get additional information?

To find out more information about federal and state law protections, contact the Cancer Legal Resource Center at 866-843-2572 or visit www.CancerLegalResourceCenter.org

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⁸ *Id* at 3-5.

⁹ i.e., a geographical area. See Affordable Care Act, Pub. L. No.148, § 2701(a)(2), 124 Stat. 119, 155 (2010).

¹⁰ *Id.*

¹¹ The ACA explicitly states genetic information as a health status factor.

¹² *Id* at 10-11.

¹³ *Genetic Discrimination*, Genome.gov (June 30, 2014), <http://www.genome.gov/10002077> (emphasis added).