

Genetic Discrimination: What Are My Rights?

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 genetic discrimination.

Why should I 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 share important information with healthcare professionals and decline early screening and preventive 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 health 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. One such circumstance is that an employer may obtain an employee’s genetic information when it offers health or genetic services as part of an *optional*

¹ A hereditary predisposition or a genetic predisposition means a person has inherited a gene that gives them 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).

wellness program.³ Another exception is if the employer accidentally overhears an employee discussing their genetic information in the office or receives information of an employee's genetic information because it is public information. However, if an employer gets access to an individual's genetic information due to one of the few exceptions stated in the law, the employer must treat this information as confidential and must not disclose it.

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 or federal employees who receive Federal Employee Health Benefit Plans.

Employee Wellness Programs and GINA

On May 17, 2016, the U.S. Equal Employment Opportunity Commission (EEOC) issued a final rule to amend the regulations implementing Title II of GINA. The final rule states that employers may provide limited financial incentives in exchange for an employee's spouse providing information about his or her current or past health status as part of a wellness program, whether or not the program is part of a group health insurance plan.

However, the final rule does not surpass other federal confidentiality laws. For example, the Health Insurance Portability and Accountability Act (HIPAA) still applies. HIPAA protects and sets limits on information about participants that can be used to identify them (e.g. birth dates or addresses) and that relate to any past or present health condition.

For more information about the EEOC's final rule on employer wellness programs and GINA, visit: <https://www.eeoc.gov/laws/regulations/qanda-gina-wellness-final-rule.cfm>

B. ADA (Americans with Disabilities Act)

The ADA prohibits discrimination in the workplace against a "qualified individual with a disability."⁴ This includes people who are perceived by others having a disability, even if they do not currently have a disability. Although a genetic predisposition to cancer or another illness is not necessarily a disability on its own, if an employer learns of an employee's family medical history, it is possible that the employee may be perceived as having a disability or impairment. For example, if an employee requests to take time off to take care of a family member who has cancer, the employer might assume that cancer runs in that person's family and may begin to perceive that employee in the same way as someone with a current disability. In these situations, the ADA prohibits discrimination against the employee based on perceived disability or association with a person

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 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 (August 9, 2017), <https://www.healthcare.gov/glossary/wellness-programs/>.

⁴ Under the ADA, an individual with a disability is defined as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. Persons discriminated against because they have a known association or relationship with a disabled individual also are protected.

with a disability. Additionally, the Equal Employment Opportunity Commission (EEOC) has interpreted the ADA to prohibit workplace discrimination of healthy persons based on genetic status.

Employee Wellness Programs and the ADA

On May 17, 2016, the U.S. Equal Employment Opportunity Commission (EEOC) also issued a final rule to amend the Regulations and the accompanying Interpretive Guidance of Title I of the ADA. The final rule says employers may provide limited financial and other incentives in exchange for an employee answering disability-related questions or taking medical examinations as part of a wellness program, whether or not the program is part of a health plan. This rule only applies to wellness programs that require employees to answer disability-related questions or to undergo medical examinations to earn a reward or avoid a penalty.

Like the requirements under GINA, this policy will apply only to employer-sponsored wellness programs on the first day of the first plan year that begins on or after January 1, 2017. Again, other federal confidentiality laws such as HIPAA still apply, so participants' information that can be used to identify them and that relate to any past or present health condition are protected. In addition, the ADA requires employers to provide reasonable accommodations that allow employees with disabilities to participate in such programs.

For more information about the EEOC's final rule on employer wellness programs and the ADA:

- <https://www.eeoc.gov/laws/regulations/qanda-ada-wellness-final-rule.cfm>
- <https://www.federalregister.gov/documents/2016/05/17/2016-11558/regulations-under-the-americans-with-disabilities-act>

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 because of a genetic predisposition to cancer, 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.⁵ Under GINA, genetic information includes genetic test results, family medical history, and the use of genetic services.

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 GINA and the Affordable Care Act, HIPAA (Health Insurance and Portability and Accountability Act) allowed group health plans to refuse to cover pre-existing conditions for up to a year, known as pre-existing condition exclusion periods. However, HIPAA also provided that genetic information on its own, without the presence of a diagnosis or manifestation of a genetic condition, could not be considered a pre-existing condition. As a result, under HIPAA, group health plans were not allowed to ask for or consider someone's genetic information. Now, under the Affordable Care Act, group health plans can no longer have pre-existing condition exclusion periods.

GINA clarifies and strengthens HIPAA nondiscrimination rules regarding genetic information and genetic testing.⁶ In other words, GINA strengthens the privacy regulations under HIPAA, and together these laws treat genetic information as confidential medical information. This prevents group, individual, Medigap, and state governmental health plans from using or disclosing an individual's genetic information.

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

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

The Patient Protection and Affordable Care Act (ACA, also known as Obamacare), created many reforms to the private health insurance market across the nation.⁷ One important change under the ACA was that a group health plan or health insurance provider can no longer set premiums or determine eligibility for coverage based on "health status factors," such as genetic information.⁸ Additionally, 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 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)

⁶ *Id* at 2.

⁷ Sarata, *supra*, at 1-7.

⁸ *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.⁹ These factors are: (1) whether an individual is seeking self or family enrollment in a plan or coverage; (2) rating area¹⁰; (3) age; and (4) tobacco use.¹¹ No other factors may be considered by a health insurance provider when determining eligibility for coverage or premium rates. Since genetic information is not listed as one of the factors, insurers may not consider this information to determine eligibility or premium rates.

The ACA and GINA both share the goal of prohibiting genetic discrimination against individuals¹²; both laws complement each other and decrease the likelihood of discrimination by prohibiting the genetic information from being used in health insurance premium and eligibility determinations.¹³

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.

www.Genome.gov provides a summary of the current state of laws regarding genetics in individual states:¹⁴ 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 override state laws with stricter protections. *[As of April 2017], 17 states have additional laws restricting the use of genetic information in determining coverage for life insurance, 17 states have laws restricting the use of genetic information for disability insurance, and 8 states have laws restricting the use of genetic information for long-term care insurance.*

⁹ *Id* at 3-5.

¹⁰ i.e., a geographical area. See Affordable Care Act, Pub. L. No.148, § 2701(a)(2), 124 Stat. 119, 155 (2010).

¹¹ *Id.*

¹² The ACA explicitly states genetic information as a health status factor.

¹³ *Id* at 10-11.

¹⁴ *Genetic Discrimination*, Genome.gov (April 17, 2017), <https://www.genome.gov/27568503/genetic-discrimination-and-other-laws/> (emphasis added).

ADDITIONAL RESOURCES

For more information about genetic discrimination:

The National Human Genome Research Institute

<https://www.genome.gov/10002077/genetic-discrimination/>

The U.S. National Library of Medicine

<https://ghr.nlm.nih.gov/primer/testing/discrimination>

The Genetic Alliance

<http://www.geneticalliance.org/advocacy/policyissues/geneticdiscrimination>

GINAHelp.org

<http://www.ginahelp.org/>

Myriad Reimbursement Assistance Program

801-584-3600

www.myriadtests.com

(Assists patients with health insurance billing and reimbursement issues for genetic testing through Myriad labs.)

National Society of Genetic Counselors

(312) 321-6834

<http://www.nsgc.org/>

FORCE: Facing Our Risk of Cancer Empowered

(866) 288-7475

www.facingourrisk.org

(A nonprofit organization and resource for women whose family history and genetic status put them at high risk for breast and/or ovarian cancer)

DISCLAIMER: This publication is designed to provide general information on the topics presented. It is provided with the understanding that the author is not engaged in rendering any legal or professional services by its publication or distribution. Although these materials were reviewed by a professional, they should not be used as a substitute for professional services. The CLRC has no relationship or affiliation with the referral agencies, organizations or attorneys to whom we refer individuals. Resources and referrals are provided solely for information and convenience. Therefore, CLRC disclaims any and all liability for any action taken by any entity appearing on CLRC's resource and referral lists.
