

Disability Rights Legal Center

CLRC

Cancer Legal Resource Center

The CLRC is a joint program of the Disability Rights Legal Center & Loyola Law School Los Angeles

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Genetics and Federal Law

What is genetic discrimination?

Genetic discrimination occurs when an individual is treated differently than others because of their hereditary predisposition to a particular disease.

Why should you care about genetic discrimination?

There is the potential for employers and insurance companies to discriminate based on a person's genetic characteristics. Because of the fear that their genetic characteristics may be used against them, some people decide not to disclose information to healthcare professionals and decline early screening and preventative measures, which may be crucial for their 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 insurance and employment arenas.

EMPLOYMENT

- **GINA (Genetic Information Nondiscrimination Act of 2008) – Employment provisions**

GINA prohibits employers, including employment agencies, labor organizations, and joint labor-management committees, from discriminating against an employee based on their genetic information. The law protects against the use of genetic information in all employment practices, including hiring, firing, job application, job assignment, training, and promotions. Employers also cannot request, require, or purchase an employee's genetic information except in limited circumstances. If an employer does possess an individual's genetic information due to one of the exceptions, they must treat such information as confidential and not disclose the information.

- **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.

- **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.

INSURANCE

- GINA (Genetic Information Nondiscrimination Act of 2008) – Insurance provisions

GINA prohibits group, individual, Medigap, and state government health plans from restricting enrollment or adjusting premiums based on genetic information. Under GINA, genetic information includes genetic test results, family medical history, and the use of genetic services. However, the definition of genetic information does not include manifested diseases, so health insurance companies can increase premiums or deny enrollment if an individual has symptoms associated with the genetic condition. Additionally, under GINA a health insurer cannot request, require, or purchase genetic information of an individual or potential insured individual. The insurance protections of GINA do not apply to life, long-term care, or disability insurance policies.

- HIPAA (Health Insurance Portability and Accountability Act)

HIPAA applies to group health insurance companies, not private individual health plans. Under HIPAA, genetic information cannot be considered a pre-existing condition. Therefore, although group health plans generally can impose pre-existing condition exclusion periods, they cannot impose these periods based only on genetic characteristics in the absence of a diagnosis or manifestation. 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. In this situation, 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.

Additionally, GINA amends the HIPAA privacy regulations. Under these laws, genetic information is considered confidential medical information. Therefore, group, individual, Medigap, and state governmental health plans are prohibited from using or disclosing the genetic information of an individual.

Genetics and New York Law

How does New York law protect people from genetic discrimination?

In addition to federal law, New York law provides many protections against genetic discrimination.

INSURANCE

Definition of Genetic Test

A genetic test is any laboratory test of human DNA, chromosomes, genes, or gene products to diagnose the presence of a genetic variation linked to a predisposition to a genetic disease or disability in the individual or the individual's offspring. The definition excludes routine tests.

Health insurance

New York law requires insurance companies to get informed consent from an individual before requesting or requiring a genetic test. Genetic information is not treated as a pre-existing condition for health insurance policies.

Life, disability and long-term care insurance

New York law requires insurance companies to get informed consent from an individual before requesting or requiring a genetic test.

EMPLOYMENT

In New York, it is unlawful for an employer to discriminate against an employee based on a predisposing genetic characteristic. Additionally, an employer cannot request or require an employee to take a genetic test unless the test specifically relates to occupational environment.

Under New York law, a predisposing genetic characteristic is any inherited gene or chromosome, or alteration thereof, and determined by a genetic test or inferred from information derived from an individual or family member that is scientifically or medically believed to predispose an individual or the offspring of that individual to a disease or disability, or to be associated with a statistically significant increased risk of development of a physical or mental disease or disability.

Where can I get additional information?

If you have questions about genetics and employment protections in New York, contact the New York State Division of Human Rights Commission at (718) 741-8400 or (866) 324-7474, or the EEOC at (800) 669-4000.

If you have questions about genetics and insurance protections in New York, contact the New York Department of Insurance at (800) 342-3736.

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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