

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 South Dakota Law

How does South Dakota law protect people from genetic discrimination?

In addition to federal law, South Dakota law provides many protections against genetic discrimination.

INSURANCE

Definition of genetic information

South Dakota law defines genetic information as information about genes, gene products, and inherited characteristics that may derive from the individual or a family member. This includes information regarding carrier status and information derived from laboratory tests that identify mutations in specific genes or chromosomes, physical medical examinations, family histories, and direct analysis of genes or chromosomes.

Health insurance

South Dakota law states that no health carrier can require or request an individual or blood relative to take a genetic test or take into consideration the fact that a genetic test was refused when determining eligibility for coverage, establishing premiums, limiting coverage, renewing coverage, or any other underwriting decision in connection with health insurance.

Life, long-term care, and disability insurance

South Dakota does not have any provisions regarding these insurance and genetics.

EMPLOYMENT

It is unlawful in South Dakota for an employer to obtain or use genetic information of an individual to discriminate or restrict any right or benefit otherwise available. Furthermore, a small employer carrier may not establish rules for eligibility for any individual to enroll under a plan, including continued eligibility, based on health status related factors, including genetic information.

Where can I get additional information?

If you have questions about genetics and employment protections in South Dakota Department of Commerce & Regulation, Division of Human Rights at (605)773-4493, or the EEOC at (800) 669-4000.

If you have questions about genetics and insurance protections in South Dakota, please contact the South Dakota Division of Insurance at (605)773-3563

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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