

Disability Rights Legal Center

CLRC

Cancer Legal Resource Center

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

Genetics and Federal Law

What is Genetic Discrimination?

Genetic discrimination refers to social or economic discrimination based on a person's hereditary predisposition to a particular disease.

Why should you be concerned about Genetic Discrimination?

There is a 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.

How does federal law protect you from Genetic Discrimination?

HEALTH INSURANCE

- **GINA (Genetic Information Nondiscrimination Act of 2008)**
 - Prohibits group health plans from restricting enrollment and adjusting premiums for health insurance on the basis of genetic information. However, the group health insurer can increase premium if an individual has symptoms associated with the genetic condition.
 - A group health plan cannot request or require an individual or family member of an individual from undergoing a genetic test.
 - A group health insurer cannot request, require, or purchase genetic information for (1) underwriting purposes or (2) with respect to any individual prior to their enrollment. However, it is not a violation if the group health insurer incidentally obtains the genetic information.
 - This law applies to all group health plans including small group health plans.
 - Prohibits individual health insurers from restricting enrollment and adjusting premiums for health insurance on the basis of genetic information. However, an individual health insurer can increase premium if the genetic predisposition is manifested.
 - A health insurer offering health insurance coverage in the individual market cannot establish eligibility rules for enrollment based on genetic information.
 - A health insurer cannot request, require, or purchase genetic information for (1) underwriting purposes or (2) with respect to any individual prior to their

enrollment. However, GINA provides that if the health insurer incidentally obtains genetic information, then that is not a violation.

- Prohibits individual health plans from imposing a pre-existing condition exclusion on the basis of genetic information.
- These requirements apply to all nonfederal governmental plans. (Not Medicaid and Medicare)
- Prohibits Medigap insurers from denying or conditioning the issuance or effectiveness of the policy, including imposing any exclusion of benefits based on a preexisting condition.
 - A Medigap insurer cannot (1) request or require an individual or family member to take a genetic test or (2) request, require, or purchase genetic information for underwriting purposes.
- **Health Insurance Portability and Accountability Act [HIPAA]**
 - Prohibits group health plans from using genetic information to determine insurance eligibility or from setting pre-existing condition coverage exclusions. Generally group health plans can impose pre-existing condition exclusions for up to 12 months (some states have enacted laws to shorten this period). However, genetic characteristics may not be treated as pre-existing conditions in the absence of a diagnosis of the conditions related to such characteristics.
 - Note: 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. For example, a plan could exclude coverage for a particular condition, such as prophylactic mastectomies, or impose lifetime caps on all benefits or specific benefits.
 - HIPAA does not apply to private individual health plans. However, some states have enacted laws that prohibit individual health plans from discriminating based on genetic characteristics. HIPAA does apply to individual HIPAA plans.
 - GINA Section 105 – HIPAA Privacy
 - Amends the Health Insurance Portability and Accountability Act of 1996 (HIPAA) privacy regulations to: (1) treat genetic information as confidential medical information such as that contained in your medical records; and (2) prohibit the use or disclosure by a group health plan, health insurance coverage, or Medicare supplemental policy of genetic information about an individual for underwriting purposes.

EMPLOYMENT

- **Americans with Disabilities Act [ADA]**
 - Prohibits discrimination in the workplace for a “qualified individual with a disability.”
 - The Equal Employment Opportunity Commission 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.

○ **GINA**

- Prohibits an employer, employment agency, labor organization, or joint labor-management committee from discriminating against an employee, individual, or member because of genetic information in all employment practices, including hiring, firing, job application, job assignment, training and promotions, or attempting to cause an employer to discriminate against a member based on their genetic information.

- An employer, employment agency, labor organization or joint labor-management committee cannot request, require or purchase an employee's genetic information, EXCEPT where (1) such information is required to comply with certification requirements of family and medical leave laws; (2) the information is to be used to genetically monitor the biological effects of toxic substances in the workplace; and (3) the information is used for law enforcement purposes.

- Requires employers that possess such genetic information about an employee to treat such information as confidential and prohibits the employer from disclosing the genetic information except:
 1. to the employee or member upon request;
 2. to an occupational or other health researcher;
 3. in response to a court order;
 4. to a government official investigating compliance with this Act;
 5. in connection with the employee's compliance with the certification provisions of family and medical leave laws; or
 6. to a public health agency.

How does state law protect you from Genetic Discrimination?

The state in which you live may provide you with additional legal protections from genetic discrimination. For example, your state may provide protections in the life and disability insurance arena. To find out more information about state law protections, contact the Cancer Legal Resource Center at 866-843-2572 or contact your state's fair employment and insurance agencies.

Where can I get additional information?

If you have additional questions about genetics and employment protections in your state, contact the Equal Employment Opportunity Commission for your state's fair employment agency. If you have questions about genetics and insurance protections in your state, contact your state's insurance agency.

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