

Quick Guide to Genetic Discrimination

Genetic information is information about your chromosomes, genes, or proteins. A genetic test can give you useful information to make decisions about your health care. For example, if you test positive for a genetic mutation that increases your chances of getting cancer, you could use that information to better manage your health through cancer screening tests, lifestyle changes, or preventive surgery. However, you may be worried about what happens if your employer or health insurer learns about the results of your test or your family medical history. **Genetic discrimination** occurs when individuals are treated differently because of their genetic information or family medical history. Key laws protect employees and consumers from genetic discrimination.

Genetic Information Nondiscrimination Act (GINA)

GINA prohibits employers and health insurance companies from negatively using an individual's genetic information. Under GINA, genetic information cannot be considered a preexisting medical condition. GINA defines genetic information as:

- any information about an individual's genetic tests or the genetic tests of a family member;
- request for and use of genetic services (e.g., genetic testing, counseling, or education); and
- the manifestation of a disease/disorder in a person's family members (also called "family medical history").

Under GINA, a family member includes any relative within four degrees of an individual (great-great-grandparents, great-great-grandchildren, and first cousins once-removed).

GINA does NOT apply to people who have already been diagnosed with a disease or disorder.

Genetic Discrimination and Work: There are three key federal laws and directives that protect you from genetic discrimination at work: the Americans with Disabilities Act, Executive Order No. 13145, and GINA.

Americans with Disabilities Act (ADA): a federal law that protects employees from discrimination based on a disability. Under the ADA, employers cannot:

- ask questions about a job applicant's medical history
- require an applicant to take a medical exam before making a job offer
- take negative employment actions against an employee who is regarded as having a disability because he or she has a genetic predisposition to cancer

For more information, read our Quick Guide to the ADA: <https://TriageCancer.org/QuickGuide-ADA>. The U.S. Equal Employment Opportunity Commission (EEOC) enforces federal fair employment protections in GINA and the ADA (www.eeoc.gov). For information about state fair employment laws, visit Triage Cancer's Chart of State Laws: <https://trriagecancer.org/statelaws>.

Executive Order (EO) No. 13145: issued by President Bill Clinton on February 8, 2000. EO 13145 prohibits discrimination in federal employment based on genetic information. Federal agencies cannot require or ask for genetic information from their applicants, employees, or former employees, nor can they use such information to make employment decisions.

Title II of GINA: prohibits employers from discriminating against employees based on genetic information, and forbids employers from requesting, requiring, or purchasing such information.

- GINA covers job applicants, current employees, and former employees.
- GINA applies to private employers with 15+ employees, employment agencies, labor organizations, joint labor-management committees, and federal, state, and local governments.
- GINA does not apply to Indian tribes and bona fide private clubs.

Under Title II, employers cannot “fail or refuse to hire, or to discharge, any employee, or otherwise to discriminate against any employee...because of genetic information with respect to the employee.” Employers also cannot:

- Harass an employee based on genetic information
- Attempt to acquire a current or prospective employee’s genetic information
- Disclose an employee’s genetic information without his or her consent

For someone who is concerned about disclosing their cancer diagnosis or genetic status at work, read our Quick Guide to Disclosure, Privacy, & Medical Certification: <https://tragecancer.org/QuickGuide-Disclosure>

Genetic Discrimination and Health Insurance: There are three key laws that address health insurance discrimination based on genetic information: the Health Insurance Portability & Accountability Act (HIPAA), GINA, and Patient Protection & Affordable Care Act (ACA).

Health Insurance Portability & Accountability Act (HIPAA): prohibits job-based health plans from denying coverage based on an employee’s genetic information.

Title I of GINA: prohibits health insurance companies and employers with self-funded health plans from discriminating against individuals based on their genetic information. Health insurers are not permitted to use genetic information to make eligibility, premium rating, underwriting, or coverage decisions. Also, health insurers cannot require individuals or their family members to take genetic tests or provide other genetic information.

- Title I of GINA applies to group health plans, individual health insurance policies, and Medigap policies (Medicare supplemental policies). However, GINA does not apply to the Indian Health Service, Veterans health plans, TRICARE, or the Federal Employees Health Benefits Program.

The Patient Protection & Affordable Care Act (ACA): prohibits health insurance companies selling individual or employer-sponsored insurance from denying someone a policy, or charging them more, based on their medical condition or genetic information.

Genetic Discrimination and Other Types of Insurance

GINA does not apply to life insurance, disability insurance, or long-term care insurance. However, some states may have state laws that protect against genetic discrimination. See the Triage Cancer Chart of State Laws: <https://tragecancer.org/StateLaws>.

Filing a Work-Related Genetic Discrimination Complaint

- *Against Private-Sector Employers and State and Local Governments:* If your rights under the ADA or GINA have been violated, you can file a complaint with the EEOC. The process can be started in person, over the phone, by mail, or online. For more information, visit: <https://www.eeoc.gov/how-file-charge-employment-discrimination>.
- *Against Federal Agencies:* If you work for or applied for a job with the federal government, filing a GINA rights complaint begins with contacting an Equal Employment Opportunity (EEO) counselor. For more information, visit: https://www.eeoc.gov/federal/fed_employees/complaint_overview.cfm.

Filing a GINA Health Insurance Complaint

To report a violation of health privacy under GINA and HIPAA, you can file a complaint with the HHS Office for Civil Rights (OCR). For more information, visit: https://ocrportal.hhs.gov/ocr/cp/complaint_frontpage.jsf.

For more information about Genetics and Genetic Discrimination, visit <https://TriageCancer.org> and <https://TriageCancer.org/Cancer-Finances-Genetics>.