



Information on the Genetic Information Nondiscrimination Act (GINA)

What GINA does:	What GINA does not do:
Prohibits use of an individual's genetic information in setting eligibility or premium or contribution amounts by group and individual health insurers.	Does not prohibit medical underwriting based on current health status. Does not mandate coverage for any particular medical tests or treatments.
Prohibits health insurers from requesting or requiring an individual to take a genetic test.	Does not interfere with the ability of a treating health care professional to request that an individual or family member undergo a genetic test. Nor does it limit the authority of a health care professional who is employed by or affiliated with a health plan or issuer from notifying an individual about genetic tests or providing information about a genetic test as part of a wellness program.
Prohibits use of an individual's genetic information by employers in employment decisions such as hiring, firing, job assignments, and promotions.	Does not subject employers to remedies and procedures that are any different from those in other civil rights laws such as Title VII and the Americans with Disabilities Act.
Prohibits employers from requesting, requiring, or purchasing genetic information about an individual employee or family member.	Does not prohibit workplace collection of genetic information for toxic monitoring programs, employer-sponsored wellness program, administration of federal and state Family and Medical Leave laws, and in certain cases of inadvertent acquisition of information. However, the employer may not use or disclose the information.

Genetics and Public Policy Center
 Johns Hopkins University
 1717 Massachusetts Ave. N.W., Suite 530
 Washington, D.C. 20036
 202.663.5971 • Fax: 202.663.5992
www.DNAPolicy.org

For more information, please contact the Genetics and Public Policy Center at GINAInfo@jhu.edu

What's covered? Definitions of Terms in GINA

The key terms in the new genetic discrimination legislation are “genetic test” and “genetic information.”

“Genetic test” means a test that assess genotypes, mutations, or chromosomal changes.

“Genetic information” means information about:

- a person’s genetic tests
- genetic tests of a person’s family members (up to and including fourth-degree relatives)
- any manifestation of a disease or disorder in a family member
- participation of a person or family member in research that includes genetic testing, counseling, or education

Genetic information does not include information about sex or age.

It is expected that federal regulations will clarify what tests are and are not protected before GINA is fully in force.

Examples of protected tests are:

- Tests for BRCA1/BRCA2 (breast cancer) or HNPCC (colon cancer) mutations
- Classifications of genetic properties of an existing tumor to help determine therapy
- Tests for Huntington disease mutations
- Carrier screening for disorders, such as cystic fibrosis, sickle cell anemia, spinal muscular atrophy, and the fragile X syndrome

During consideration of the new law, a group of scientists and healthcare providers looked at the definition in the bill and compared it to a list of the most-frequently-ordered laboratory tests to make sure they were not accidentally swept into the bill’s definition.

Routine tests such as complete blood counts (CBC, or blood panel), cholesterol tests, and liver-function tests are not protected under GINA. Also not protected are analysis, including DNA analysis, of infectious agents such as bacteria, viruses, and fungi. An HIV test, for example, is not covered. Although it is a retrovirus that inserts itself into human DNA, HIV is not itself human DNA and measuring its presence does not constitute a genetic test under the law’s definition.

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Scope and Enforcement

- GINA amends the Employee Retirement Income Security Act (ERISA), the Public Health Services Act (PHSA), the Health Insurance Portability and Accountability Act (HIPAA), and the Internal Revenue Code, and applies to employers covered by Title VII. GINA's provisions – including its enforcement mechanisms and penalties – were written to be consistent with provisions of these laws. Final regulations will be developed and the law will be enforced by federal agencies including the Department of Health and Human Services, the Department of Labor, and the Equal Employment Opportunity Commission.
- GINA does not apply to members of the United States Military, to veterans obtaining health care through the Veteran's Administration, or to the Indian Health Service, because the laws amended by GINA do not apply to these groups and programs.
- GINA does not include protection from genetic discrimination in life insurance, disability insurance, or long-term-care insurance.

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