

Update

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New law bars genetic bias in employment, health plans

New restrictions apply to genetic information used for employment and health benefit purposes as a result of the Genetic Information Nondiscrimination Act (GINA). Signed into law May 21, GINA's employment-related protections go into effect Nov. 21, 2009, and its health benefit provisions take effect for plan years starting on or after May 21, 2009. This *Update* highlights key provisions of the new law for employers and their health benefit plans.

Scope of law

GINA ([Pub. L. No. 110-233](#)) generally restricts the acquisition, use and disclosure of an individual's genetic information by employers, group health plans and health insurers. The law also strengthens confidentiality protections for genetic records.

Protected genetic information. Under GINA, genetic information includes genetic tests, counseling or education requested or received by an individual or family member. GINA also covers an individual's family medical history – that is, any disease or disorder affecting a member of an individual's family. The definition of family members extends to spouses; dependents, including foster or adopted children; and relatives to the fourth degree (for example, a great-great grandparent). GINA's protections also apply to genetic information about a fetus or an embryo in some situations.

Covered employers, plans. The law's employment provisions apply to employers, labor organizations and employment agencies subject to Title VII of the Civil Rights Act of 1964 (the major federal employment anti-bias law), as well as government employers covered by similar laws. GINA's insurance provisions cover the following:

- Insured or self-insured group health plans subject to the Employee Retirement Income Security Act (ERISA) and the Internal Revenue Code's health status nondiscrimination requirements

Enforcement, penalties and state law interaction

Employment provisions. GINA largely adopts the complaint procedures, remedies and penalties available under Title VII for private-sector employees and similar anti-bias laws for public-sector workers. Remedies include hiring or reinstatement, compensatory damages and, for intentional discrimination, punitive damages. For now, however, GINA does not permit disparate impact claims (where a seemingly neutral employment practice disproportionately affects a protected class of employees).

Health benefit provisions. Group health plans subject to ERISA that violate GINA can face daily penalties of up to \$100 per affected participant or beneficiary. However, depending on the nature of the violation and the corrective action taken, penalties can range from \$0 to at least \$15,000 per person and a maximum of \$500,000.

Remedies for HIPAA's privacy violations and penalties for violation of HIPAA's nondiscrimination rules also extend to genetic information protected by GINA.

State law interaction. GINA generally does not pre-empt any state law that provides greater nondiscrimination protection for genetic information.

- Group and individual-policy health insurers and nonfederal government plans subject to the Public Health Service Act or the Social Security Act's Medigap provisions

GINA's changes to the Health Insurance Portability and Accountability Act also affect covered entities under HIPAA's privacy and security rules.

Employment nondiscrimination protections

Prohibited uses of genetic information. GINA mirrors Title VII by barring the use of genetic information to deny a job, fire or otherwise discriminate in compensation, benefits, training, or other employment terms or conditions. Employers also cannot use genetic information to classify employees in a way that adversely affects their employment opportunities or status. Current legal actions and remedies for illegal employment bias generally extend to genetic discrimination (see sidebar on this page).

Restricted employer access to genetic information. Under GINA, employers generally cannot require, request or purchase genetic information about an employee or family member. Despite limited exemptions for workplace health or genetic monitoring programs (see sidebar on page 3), the law generally bars employer access to individually identifiable genetic information. However, no GINA violation occurs in certain situations, including when an employer requests or requires family medical information to comply with the federal Family and Medical Leave Act and similar state laws.

Confidentiality protections. Employers must maintain genetic information in confidential, restricted-access files kept apart from other personnel records. This rule can be satisfied by complying with the Americans with Disabilities Act (ADA) protections for medical records.

Group health plan restrictions

Under GINA, group health plans and insurers cannot require individuals to undergo genetic testing, although a narrow exception allows asking enrollees to voluntarily participate in genetic research. While genetic test results can be used for claims substantiation or other payment purposes, health plans and insurers cannot require, request or purchase anyone's genetic information before enrollment or use that information for these underwriting purposes:

- To determine eligibility for enrollment or continued coverage
- To impose pre-existing condition exclusions

- To vary individual or group premiums or contribution rates
- To conduct other activities related to designing, renewing or replacing health benefits or insurance contracts

Health plans and insurers that inadvertently acquire genetic information do not violate the law as long as they don't use this information for underwriting. Once an enrollee has a disease or disorder, pre-existing exclusions can apply to it, and the manifested disease or disorder can be used to increase the employer's group premium accordingly. Moreover, plans may request genetic information after an individual has enrolled in the plan.

HIPAA privacy and security clarification. GINA amends HIPAA's privacy and security rules to explicitly include genetic information as a type of protected health information (PHI). This modification makes clear that HIPAA's protections also extend to someone's family medical information, and health plans and other covered entities cannot use genetic information for underwriting purposes.

Next steps

As a law aimed largely at allaying fears that genetic testing could lead to future discrimination, GINA's full implications for employers' current practices related to family medical histories, biometric screenings and other genetic information remain to be seen. Within the next year, the Equal Employment Opportunity Commission must issue final rules on GINA's employment provisions, while the Labor, Treasury, and Health and Human Services departments are to do the same for the law's health provisions. Employers should keep an eye out for these regulations, which are likely to help clarify the scope of GINA's impact. In the interim, employers may want to consider taking the following steps:

- Identify current practices that involve requests for genetic or family medical information, such as family and medical leave certifications, health risk assessments or fitness-for-duty activities.
- Consider whether the new protections will lead to more participant requests for genetic testing and how that could affect a group health plan's costs or coverage.
- Assess how genetic information is currently stored and maintained.
- Ensure employment decisions are not based on genetic information.

Permitted requests for genetic information in the workplace

Health or genetic services.

GINA allows genetic information requests as part of employer-sponsored health or genetic services, such as wellness programs or health risk assessments, if several requirements are met:

- Participants must give voluntary, written authorization in advance.
- Genetic information is shared only with the individual and the program's licensed health professional or board-certified genetic counselor.
- Employers receive only aggregated and de-identified program information.

Genetic monitoring. Genetic screening for the effects of toxic workplace substances is permitted under certain conditions:

- Employees receive written notice of the monitoring.
- Unless monitoring is legally required, employees voluntarily consent in writing to monitoring.
- The monitoring conforms to any applicable federal or state regulations.
- Employees receive monitoring results.
- Employers receive only aggregated and de-identified test results.



For more information

For additional information, please contact your Mercer consultant.

*This **Update** is for information only and does not constitute legal advice; consult with legal and tax advisers before applying this information to your situation.*

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