



## >> The Genetic Information Nondiscrimination Act (GINA)

On May 21, 2008, the President signed the Genetic Information Nondiscrimination Act (GINA) into law. Title I of GINA addresses the use of genetic information in health insurance. Title II of the Act prohibits the use of genetic information in employment, prohibits the intentional acquisition of genetic information about applicants and employees, and imposes strict confidentiality requirements. The provisions of GINA related to health coverage are effective as of May 21, 2009 and those related to employment are effective as of November 21, 2009.

Title I applies to health insurers and health plans. Title II applies to private, state, and local government employers with 15 or more employees, employment agencies, labor unions, and joint labor-management training programs. It also covers Congress and federal executive branch agencies.

### What is Genetic Information?

GINA defines *genetic information* as information about:

- An individual's genetic tests (including tests for colon cancer, breast cancer, Huntington's Disease, Sickle Cell anemia, etc.);
- Genetic tests of an individual's family members (defined as dependents and up to and including 4th degree relatives);
- Genetic tests of any fetus of an individual or family member who is a pregnant woman, and genetic tests of any embryo legally held by an individual or family member utilizing assisted reproductive technology;
- The manifestation of a disease or disorder in an individual's family members (family history); or
- Any request for, or receipt of, genetic services or participation in clinical research that includes genetic services (genetic testing, counseling, or education) by an individual or an individual's family members.

Genetic information does not include information about the sex or age of an individual or the individual's family members, or information that an individual *currently has* a disease or disorder. Genetic information also does not include tests for alcohol or drug use.

### Genetic Discrimination in Employment

Title II of GINA prohibits use of genetic information in making decisions related to any terms, conditions, or privileges of employment, prohibits covered entities from intentionally acquiring genetic information, requires confidentiality with respect to genetic information (with limited exceptions), and prohibits retaliation.

#### *Unlawful Employment Decisions*

The law prohibits the use of genetic information in employment decisions, including hiring; firing; job assignments; and promotions by employers, unions, employment agencies, and labor-management training programs.

### *Acquisition of Genetic Information*

Employers may not request, require, or purchase genetic information with respect to an employee/applicant or family member of an employee/applicant. One exception to this rule applies to inadvertent acquisition of genetic information, such as overhearing an employee conversation, receiving genetic information verbally when asking a general question about an employee's health, or receiving unsolicited genetic information as part of a documented request for a disability accommodation or leave of absence.

### *Confidentiality*

Covered entities in possession of genetic information about applicants or employees must treat it the same way they treat medical information generally. They must keep the information confidential and, if the information is in writing, must keep it apart from other personnel information in separate medical files. A covered entity may keep genetic information in the same file as medical information subject to the Americans with Disabilities Act.

### **Genetic Discrimination in Health Insurance**

GINA prohibits health insurers from engaging in three practices:

- (1) using genetic information about an individual to adjust a group plan's premiums, or, in the case of individual plans, to deny coverage, adjust premiums, or impose a preexisting condition exclusion;
- (2) requiring or requesting genetic testing; and
- (3) requesting, requiring, or purchasing genetic information for underwriting purposes.

### *Discrimination in Premium Setting and Eligibility*

GINA prohibits health plans, group and individual health insurers and issuers, and issuers of Medicare supplemental policies from adjusting a group or individual's premium based on genetic information about an individual in the group, an individual seeking individual coverage, or an individual's family members. It also prohibits individual insurers from conditioning eligibility or continuing eligibility on genetic information, and prohibits individual insurers from treating genetic information as a preexisting condition. Issuers of supplemental Medicare policies may not deny or condition the issuance of a policy based on genetic information (and may not impose a preexisting condition exclusion based on genetic information).

### *Unlawful Genetic Testing Requirements*

GINA prohibits health plans, group and individual health insurers and issuers, and issuers of Medicare supplemental policies from requesting or requiring that individuals or their family members undergo a genetic test. This prohibition does not limit the authority of a health care professional to request that an individual undergo genetic testing as part of his or her course of health care. The act provides for a research exception to this provision, by allowing a group or individual insurance issuer to request, but not require, an individual to undergo genetic testing if specific conditions are met.

### *Restricted Collection and Use of Genetic Information*

GINA prohibits health plans, group and individual health insurers and issuers, and issuers of Medicare supplemental policies from requesting, requiring, or purchasing genetic information for the purposes of underwriting prior to an individual's enrollment or in connection with enrollment. "Incidental collection" of genetic information would not be considered a violation.