

The GINA is out of the Bottle: The Genetic Information Nondiscrimination Act Becomes Law

Thirteen years after it was first introduced, the Genetic Information Nondiscrimination Act (“GINA”) was signed into law on May 21, 2008 by President Bush. GINA establishes a uniform set of rules against genetic-based discrimination applicable to employers and health insurers. A patchwork of variable state laws previously governed this issue. Forty-one states already have laws prohibiting genetic discrimination in health insurance and thirty-one states have laws prohibiting genetic discrimination in the workplace. The Act will not preempt state laws that provide greater protection against genetic discrimination to covered individuals.

Prohibited Employment Discrimination (Title II)

The employment provisions of GINA apply to private sector employers covered by Title VII of the Civil Rights Act (those with 15 or more employees), public sector employers, employment agencies, and labor organizations. GINA mirrors the language of other employment discrimination laws such as Title VII and makes it unlawful for an employer to discriminate in any terms or conditions of employment because

of an employee’s (or an applicant’s) “genetic information.” GINA does not, however, create a cause of action for disparate impact discrimination. Like Title VII and other federal anti-discrimination employment laws, GINA also prohibits retaliation against employees who complain of genetic discrimination or otherwise participate in the enforcement of rights under the Act.

Under GINA, “genetic information” means:

- An individual’s genetic tests;
- The “genetic tests” of family members of an individual; and
- The manifestation of a disease or disorder in family members of the individual.

“Genetic information” also includes any request for or receipt of genetic services or participation in clinical research which includes genetic services. The law specifically excludes information about an individual’s age or sex from the term “genetic information.” A “genetic test” is an analysis of human DNA, RNA, chromosomes, proteins and metabolites that detects genotypes, mutations or chromosomal changes. The term “family member” is broadly defined to include relatives of the employee or the



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employee's dependents from the first to the fourth degree.

GINA further prohibits employers from requesting, requiring or purchasing genetic information with respect to an employee or an employee's family member, with some exceptions. The exceptions are as follows:

- An inadvertent request or requirement;
- Where genetic services are offered as an employee benefit and certain requirements are met;
- Where an employer requests or requires family medical history from the employee to comply with the certification provisions of the Family and Medical Leave Act;
- Where the information is to be used for genetic monitoring of the biological effects of toxic substances in the workplace, if certain requirements are met; and
- Where the employer conducts DNA analysis for law enforcement purposes as a forensic laboratory or for purposes of human remains identification, and requests or requires genetic information of such employer's employees, but only to the extent that such genetic information is used for analysis of DNA identification markers for quality control to detect sample contamination.

GINA's Confidentiality Requirements

GINA specifies that any genetic information obtained by an employer must be treated as part of the employee's confidential medical record. As with all confidential employee medical information, genetic information must be maintained on separate forms and in files kept separately from other employee information. Such files should be secured so that only those with a legitimate right to see such information may have access.

The Act also prohibits employers' disclosure of employee genetic information, but provides some exceptions, such as disclosure:

- to the employee (or family member if the family member is receiving the genetic services) at the written request of the employee;
- to an occupational or other health researcher if the research is conducted in compliance with federal regulations;
- in response to a court order, except that:
 - the employer may disclose only the genetic information expressly authorized by such order; and
 - if the court order was secured without the knowledge of the employee to whom the information refers, the employer shall inform the employee of the court order and any genetic information that was disclosed pursuant to such order;
- to government officials who are investigating compliance with GINA, if the information is relevant to the investigation;
- to the extent that such disclosure is made in connection with the employee's compliance with the certification provisions of the FMLA; or
- to a Federal, State, or local public health agency information that concerns a contagious disease that presents an imminent hazard of death or life-threatening illness. The employee must be notified of such disclosure.

Further, GINA specifies that it does not prohibit an employer who is a "covered entity" under the Health Insurance Portability and Accountability ("HIPAA") regulations from any use or disclosure of health information that is authorized for the covered entity by HIPAA regulations.



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Remedies and Enforcement

GINA will be enforced by the Equal Employment Opportunity Commission (“EEOC”) and the enforcement procedures of Title VII shall be used. Employees will be required to file a timely charge of discrimination before pursuing a lawsuit. Damages available under GINA also correspond with those established by the 1991 Civil Rights Act amendments, which authorize compensatory and punitive damages, but place limits on the amount of punitive damages based on the defendant employer’s size (ranging from \$50,000 to employers with less than 101 employees to \$300,000 for employers with more than 500 employees). GINA also provides for the recovery of reasonable attorneys’ and experts’ fees.

Effective Date and Employer Action

GINA will become effective 18 months from the date of its enactment, in November 2009. The EEOC must issue final regulations to carry out the Act no later than 1 year after the enactment date. In the

meantime, employers should: 1) begin the process of revising their nondiscrimination policies to incorporate non-discrimination on the basis of genetic information and non-retaliation language; 2) determine whether they currently request or have access to applicant or employee genetic information; 3) if so, ensure they will properly request, receive and store information once GINA becomes effective. Applicants and employees should not be requested to provide family medical histories, nor should employers request genetic information from employers for non-FMLA periods of leave. GINA will require development or revision of policies and procedures regarding personnel and medical record confidentiality, nondisclosure and maintenance.

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