

## **Regulations Interpret Genetic Information Nondiscrimination Act**

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The Genetic Information Nondiscrimination Act (GINA) sections which apply to employers come into effect on November 21, 2009. This Act will prevent employers from taking adverse action against an applicant or an employee based on his or her genetic makeup, and prohibit the collection of genetic information in many circumstances. The Equal Employment Opportunity Commission has issued proposed regulations which interpret GINA. The 60 day comment period on these proposed regulations began on March 2, 2009.

### **Discrimination Prohibited**

GINA specifically prohibits discrimination against applicants and employees (hereinafter shorted to “employees”) based on genetic information. Genetic information includes information about

- 1) the employee’s genetic tests,
- 2) the genetic tests of family members of an employee, and
- 3) the manifestation of a disease or disorder in *family members* of an employee<sup>1</sup>

The proposed regulations define *family members* to include the employee’s dependents, family members to the fourth degree (including great aunts and uncles, great-great grandparents and first cousins once removed).

Generally, under GINA, it is an unlawful employment practice for an employer or an employment agency to do any of the following:

- (1) refuse to hire or to discharge any employee because of *genetic information* of the employee;
- (2) to otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee because of his or her genetic information
- (3) to limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee as an employee, because of

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<sup>1</sup> Manifestation is defined in the proposed regulations as meaning that a person has been or could reasonably be diagnosed with the disease, disorder, or pathological condition.

the genetic information of that employee.

**Genetic information** is defined in the proposed regulations as information about a person's genetic tests,<sup>2</sup> the manifestation of disease or disorder in family members, or a person's request for or receipt of genetic services (including services that are part of clinical research). This section does not prohibit employer practices that could have an adverse impact based on genetic information. The proposed regulation makes it clear that GINA prohibits retaliation based on a person's opposition to an act made unlawful under GINA.<sup>3</sup>

### **Acquisition of Genetic Information**

Employers and employment agencies are also prevented under GINA from acquiring genetic information regarding an employee or a family member of the employee, with certain narrow exceptions. Exceptions include situations where:

- (1) an employer inadvertently requests or requires **family medical history** of the employee or family member of the employee;
- (2) the information is needed in connection with health or genetic services offered by the employer, and the employee provides authorization for access
- (3) family medical history is requested for the certification provisions of the Family and Medical Leave Act or state family and medical leave laws; OR
- (4) an employer purchases documents that are commercially and publicly available that include family medical history

**Family medical history** is defined by the proposed regulations as information about the manifestation of a disease or disorder in a family member. The Senate Report on GINA specifically references the American medical Association's adult family history form as a record of a person's family medical history.<sup>4</sup>

Keep in mind that even if the employer's acquisition of genetic information falls under one of these exceptions, the employer still cannot use the information to discriminate.

The first exception regarding an inadvertent request removes liability if a manager unintentionally acquires information about an employee, or if the information is obtained as part of documentation provided to support a certification of ability to return to work, a request for an accommodation or leave.<sup>5</sup> For example, if a manager asks an employee "How are you?" and the response includes family medical history, that employer would not be liable. Even though this exception exists, an employer seeking documentation of a need for an accommodation or leave is

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<sup>2</sup> Genetic tests are proposed to include an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes.

<sup>3</sup> Section 1635.7 of proposed regulations.

<sup>4</sup> S. Rep. No. 110-48, at 16.

<sup>5</sup> Section 1635.8 of proposed regulations.

advised to instruct the health care professional to exclude family medical history. In addition, the exception would not exclude liability based on an employer's request for family medical history as part of a post-offer medical examination allowed under the Americans with Disabilities Act (ADA).

The second exception allows for the receipt of genetic information in collection with an employee's voluntary participation in a wellness program, meaning that the employee is not penalized for not participating.

An employer would not be liable under the fourth exception if the genetic information of an employee's family is published commercially and the employer obtains that publication. The proposed regulations would include electronic as well as printed publications.

In addition to these four exceptions, employers may be allowed to request, require, or purchase genetic information with respect to an employee or a family member of the employee where the information is to be used for genetic monitoring of the biological effects of toxic substances in the workplace, with certain restrictions on such monitoring. Genetic monitoring is defined in the proposed regulations as the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations.

## **Health Information**

GINA also amends the Health Insurance Portability & Accountability Act (HIPAA) to ensure that genetic information will be treated as health information. Genetic information can be kept with other medical information that is kept confidential as required by the ADA.<sup>6</sup> This requirement would not apply to genetic information that was obtained through a commercial publication.<sup>7</sup>

Exceptions to this restriction on disclosure include release to the following:

- 1) the individual described in the information, based on a written request
- 2) occupational health researcher
- 3) a party named in a court order for its release
- 4) government officials investigating GINA compliance
- 5) employer representatives who need the information to respond to a FMLA request
- 6) public health officials investigating a contagious disease

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<sup>6</sup> 29 C.F.R. § 1630.14(c)(1).

<sup>7</sup> Section 1635.9(a) of proposed regulations.

To prepare for the implementation of GINA, employers are advised to do the following:

- Update non-discrimination policies to include genetic information as a protected category (similar to protection against discrimination based on disability, sex or race)
- Educate supervisors and managers that they cannot take an adverse action against applicants and employees based on genetic information
- Inform both managers and health care providers that they cannot require applicants or employees to submit to genetic testing or to provide family medical history unless a specific exception applies
- Maintain the confidentiality of genetic information that is gathered.

For the text of GINA, visit <http://www.govtrack.us/congress/billtext.xpd?bill=h110-493&show-changes=0&page-command=print>. For the text of the proposed regulations, visit <http://edocket.access.gpo.gov/2009/E9-4221.htm>.