



## **Introducing GINA – The Genetic Information Non-discrimination Act**

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The Genetic Information Non-discrimination Act (“GINA”) prohibits, in health plans and employment, discrimination on the basis of genetic information. GINA also contains broad restrictions on the collection and storage of genetic information, which includes family medical history.

### **Does an employer need to be aware of this law if it doesn’t perform genetic testing or actively collect genetic information?**

**YES!** Your company may currently possess, or obtain in the future, genetic information regarding employees (the definition of “employee” includes applicants for employment.) GINA does not only apply to genetic testing - genetic information also includes information obtained regarding the family medical history of an employee. GINA’s privacy protections are broader than those under the Americans with Disabilities Act (“ADA”) and the Health Insurance Portability and Accountability Act (“HIPAA”). GINA’s privacy, discrimination and retaliation provisions apply to all employers subject to GINA.

### **To which employers does Title II of GINA apply?**

Title II, effective November 21, 2009, applies to private, state and local government employers with 15 or more employees. Be aware, however, that many states have enacted similar laws, which may apply to employers with less than 15 employees.

### **What is considered genetic information under GINA?**

- information about an employee’s genetic tests
- information about the genetic tests of an employee’s family member, such as to determine whether someone is at increased risk of acquiring a condition (such as some forms of breast cancer) in the future;
- information about the manifestation of any disease, disorder or condition of an employee’s family members (family medical history).

Information about an employee’s current disease or illness is not considered genetic information, although such disease or illness may render an employee disabled under federal or state disabilities law. Genetic information does not include information about the sex or age of any individual.

## **What types of employment documents might contain genetic information?**

Family medical history may be contained in a variety of documents, including but not limited to leave requests, disability accommodation requests, post-offer, pre-employment health history questionnaires or examinations, bereavement requests, and applications for company sponsored health care or wellness programs.

## **With respect to employers, what does GINA prohibit?**

Title II of GINA prohibits discrimination against employees or applicants because of genetic information. GINA prohibits:

- the use of genetic information in employment decisions;
- the acquisition of genetic information by employers and others;
- the release of genetic information; and
- retaliation against individuals who oppose actions made unlawful by GINA or who participate in proceedings to vindicate rights under the law or aid others in doing so.

For additional information regarding GINA, including exceptions, confidentiality requirements, disclosure and procedural information, scroll down to the Supplement, or simply click [here](#).

## **WHAT SHOULD EMPLOYERS DO NOW?**

### **Update policies, handbooks, applications and training manuals**

Ensure that “genetic information” is included as a basis for prohibited discrimination in your anti-discrimination policies. A catch-all provision that includes protection from discrimination based upon “any other basis protected by law,” or something to that effect, may be sufficient in the short term, but the better practice is to revise all materials to specifically include “genetic information.” Claims of “genetic discrimination” should be added to waivers and releases. Review all documents to make sure that genetic information is not solicited. Questions regarding family medical history should be removed from any applications, health risk assessments and wellness programs. Vendors of these programs should also be contacted to ensure that such information is not solicited.

**Note** – don’t forget state law! Many states have enacted some type of genetic non-discrimination laws. Make sure your policies, handbooks and training manuals comply with the state laws in all states in which your company has employees.

### **Ensure confidentiality of lawfully acquired genetic information**

Review personnel files and ensure that lawfully acquired genetic information is not contained in personnel files, but in separate, confidential files.

## **Provide training regarding GINA to supervisors and managers**

Training about GINA, including interview guidelines, should be provided to managers and supervisors, to ensure that they do not elicit genetic information. Managers and supervisors must understand that discrimination based upon genetic information is prohibited, and that they should not inquire about genetic information in their interactions with employees unless there is a specific job-related purpose that falls within one of the exceptions to GINA. Managers and supervisors should understand how genetic information must be stored and the limited circumstances under which it can be released. For example, a request for bereavement leave which indicates that an employee's grandmother died of ovarian cancer contains family medical history, and should be kept separate from his/her personnel file. In addition, disclosure to others of the fact that the employee's grandmother died of ovarian cancer could violate GINA as it discloses family medical history.

## **Post information regarding GINA**

Employers must post information regarding GINA. The updated EEOC poster, which also includes information related to the amendments to the Americans with Disabilities Act ("ADA") as well as supplements to the current EEOC poster, are available on the EEOC's website at [http://www.eeoc.gov/employers/upload/eeoc\\_self\\_print\\_poster.pdf](http://www.eeoc.gov/employers/upload/eeoc_self_print_poster.pdf). Copies of the poster may also be ordered directly from the EEOC, or a supplement to the old poster may be downloaded at <http://www1.eeoc.gov/employers/poster.cfm>.

Both the poster and the supplemental poster are also available in Spanish, Arabic, and Chinese.

## **SUPPLEMENT**

### **What are the exceptions to the prohibition of the acquisition of genetic information under Title II?**

- where an employer inadvertently acquires family medical history of the employee or family member of the employee;
- where the genetic information is acquired through health or genetic services, if certain specified conditions are met;
- when an employer requests or requires family medical history from the employee to comply with the Family Medical Leave Act or similar state laws;
- where an employer purchases documents that are commercially and publicly available (such as newspapers, magazines or books, but not medical databases or court records) which include family medical history;
- where the information is to be used for genetic monitoring of the biological effects of toxic substances in the workplace, but only under certain specified conditions;
- where the employer conducts DNA analysis for law enforcement purposes or for purposes of human remains identification, but only to the extent that such genetic information is used for analysis of DNA identification markers for quality control to detect sample contamination.

## **What are the confidential record-keeping requirements of GINA?**

Similar to the ADA's confidentiality requirements for the storage of medical information, if an employer possesses genetic information about an employee, the information must be kept on separate forms, in separate medical files, and must be treated as a confidential medical record of the employee.

## **Can genetic information be disclosed under Title II of GINA?**

Genetic information cannot be disclosed except:

- to the employee (or family member if the family member is receiving the genetic services) based upon the employee's written request;
- to an occupational or other health researcher if the research complies with part 46 of Title 45 of the Code of Federal Regulations;
- in response to a court order, but only that information expressly authorized by the court order and, if the court order was secured without the employee's knowledge, the employer must inform the employee of the order and any genetic information that was disclosed pursuant to the court order;
- government officials investigation compliance with GINA if the information is relevant;
- in connection with the employee's compliance with the FMLA or similar state laws (but not for employer-provided leave);
- to a Federal, State, or local public health agency, only with regard to certain information and that concerns a contagious disease that presents an imminent hazard of death or life-threatening illness, and if the employee is notified of such disclosure.

## **What are the remedies under GINA?**

The same remedies available under Title VII are available under Title II of GINA - reinstatement, hiring, promotion, back pay, injunctive relief, pecuniary and non-pecuniary damages (including compensatory and punitive damages) and attorneys' fees and costs. Title VII's cap on combined compensatory and punitive damages also applies to actions under Title II of GINA.

## **Who has authority over Title II of GINA?**

The Equal Employment Opportunity Commission ("EEOC") has regulatory authority over Title II and has issued proposed regulations. The same procedures available under Title VII apply to GINA, such as the exhaustion of administrative remedies. GINA claimants can not go directly to court; they must first file a charge of discrimination with the EEOC.

## **Can a claim of disparate impact be filed under GINA?**

GINA specifically states that a cause of action for “disparate impact” on the basis of genetic information does not exist under GINA. However, Congress has six years to appoint a commission to review scientific developments and make recommendations on whether to add liability based upon disparate impact.

For additional information:

For the text of the law: <http://www.eeoc.gov/laws/statutes/gina.cfm> For the EEOC’s proposed regulations: <http://edocket.access.gpo.gov/2009/E9-4221.htm>

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