



# Legislative Brief

## Final Genetic Information Nondiscrimination Rule for Employers

### EXECUTIVE SUMMARY

On November 9, 2010, the Equal Employment Opportunity Commission (EEOC) issued a final rule to implement Title II of the Genetic Information Nondiscrimination Act of 2008 (GINA). **Title II** is designed to protect job applicants, current and former employees, labor union members, apprentices and trainees from discrimination based on their genetic information. The final rule is effective on **January 10, 2011**.

Specifically, the final rule:

- Clarifies important definitions related to the use of genetic information;
- Provides more detailed information on activities prohibited by GINA;
- Contains specific rules on when employers can and cannot acquire genetic information; and
- Requires that employers post notice of employees' rights regarding genetic information.

This Fickewirth and Associates Legislative Brief provides a summary of the final rule. Please read below for more information and contact your F&A representative with any questions.

### OVERVIEW OF THE FINAL GINA REGULATIONS

#### **Background**

President George W. Bush signed GINA into law on May 21, 2008. GINA was enacted in response to the significant advances in the field of genetics and increased use of genetic information, as well as the general public's concerns about misuse of that information.

**Title I** of GINA relates to health coverage. It applies to group health plans, health insurance issuers and Medigap insurance issuers. The Title I rules prohibit discrimination in group premiums and plan eligibility based on genetic information. They also limit the genetic information that health plans can collect. The Title I rules were effective for plan years beginning on or after May 21, 2009.

**Title II** of GINA prohibits use of genetic information in the employment context. It also restricts employers from acquiring genetic information and strictly limits disclosures of the information. Title II was effective as of November 21, 2009.

The EEOC published a proposed rule to implement Title II on March 2, 2009. After reviewing comments and coordinating with other entities, including the National Human Genome Research Institute (NHGRI) and the Departments of Labor, Health and Human Services and Treasury, the EEOC released the final rule on November 9, 2010.

#### **Who is Subject to the Final Rule?**

The final rule applies to what are known as "**Covered Entities**." A Covered Entity is an employer, employing office, employment agency, labor organization or joint labor-management committee. The Covered Entities that are subject to Title II of GINA should not be confused with those covered by the HIPAA Privacy and Security Rules, such as health plans and health insurance issuers. While the terminology is the same, the definitions are different.



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An employer is any person or entity that employs an employee. However, Indian tribes and bona fide, tax-exempt private clubs (other than a labor organization) are not considered employers.

In general, an **employee** is an individual employed by a person or entity engaged in an industry affecting commerce who had 15 or more employees for each working day in each of 20 or more calendar weeks in the current or preceding year. The term “employee” also includes certain government employees.

### What Activities are Prohibited?

The practices prohibited by the final rule in general, to some extent, will be dependent on the type of Covered Entity:

- **Employers:** may not discriminate against an individual on the basis of the individual’s genetic information for hiring, discharge, compensation, or terms, conditions or privileges of employment.
- **Employment agencies:** may not fail or refuse to refer an individual for employment or discriminate against any individual because of his or her genetic information.
- **Labor organizations:** may not exclude or expel from membership, or otherwise discriminate against, any individual because of his or her genetic information.
- **Covered entities that control apprenticeship, training or re-training programs:** may not discriminate against any individual with respect to admission to, or employment in, any such program because of the individual’s genetic information.

In addition, Covered Entities may not do the following because of an individual’s genetic information:

- Limit, segregate or classify an individual in a way that would deprive him or her of employment opportunities or affect his or her employment status;
- Fail or refuse to refer an individual for employment in a way that affects the individual’s employment opportunities or status; or
- Cause or attempt to cause another Covered Entity to impermissibly discriminate against an individual.

Finally, Covered Entities may not retaliate against an individual because the individual has opposed any activity that violates the final rule, or because he or she made a charge, testified, assisted or participated in an investigation, proceeding or hearing relating to GINA.

### What Exactly is Genetic Information?

The final rule contains additional guidance regarding the information that is protected. Under the final rule, **genetic information** means information about:

- Genetic tests of an individual or the individual’s family members;
- The manifestation of a disease or disorder in an individual’s family members (family medical history);
- An individual’s request for, or receipt of, genetic services, or the participation in clinical research involving genetic services by the individual or a family member; or
- The genetic information of a fetus carried by an individual or a family member or legally held by an individual or family member using an assisted reproductive technology.

However, genetic information does not include information about the sex or age of the individual or any family members. It also does not include information about the race or ethnicity of the individual or family members that is not derived from a genetic test.

The final rule also includes more information on some of the aspects of the definition of genetic information. For example, it includes several examples to clarify the meaning of the term **genetic test**. In general, a genetic test is an analysis of human DNA, RNA, chromosomes, proteins or metabolites that detects genotypes, mutations or chromosomal changes. Genetic tests include, but are not limited to, the following:

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- Tests to determine whether someone has a predisposition to breast cancer, hereditary nonpolyposis colon cancer, or Huntington's disease;
- Carrier screening for adults to determine the risk of conditions like cystic fibrosis, sickle cell anemia, spinal muscular atrophy or fragile X syndrome in future offspring;
- Amniocentesis and other evaluations used to determine whether a fetus has a genetic abnormality;
- Newborn screening tests to detect or indicate genotypes, mutations or chromosomal changes;
- Preimplantation genetic diagnosis performed on embryos created using in vitro fertilization;
- Pharmacogenetic tests that detect genotypes, mutations, or chromosomal changes that indicate how an individual will react to a drug or a particular dosage of a drug;
- DNA testing to detect genetic markers that are associated with information about ancestry; and
- DNA testing that reveals family relationships, such as paternity.

The following tests and procedures are not considered genetic tests:

- Analysis of proteins or metabolites that does not detect genotypes, mutations or chromosomal changes;
- A medical examination that tests for the presence of a virus that is not composed of human DNA, RNA, chromosomes, proteins or metabolites;
- A test for infectious and communicable diseases that may be transmitted through food handling; and
- Complete blood counts, cholesterol tests and liver function tests.

A test for the presence of alcohol and illegal drugs is not a genetic test. However, a test to determine whether a person has a genetic predisposition to alcoholism or drug use is a genetic test.

**Genetic services** include genetic tests, genetic counseling (including obtaining, interpreting or assessing genetic information) or genetic education.

**Family members** include an individual's dependents (as a result of marriage, birth, adoption or placement for adoption) and relatives through the fourth degree. The rule specifies the degrees of relation as follows:

- **First-degree:** parents, siblings and children.
- **Second-degree:** grandparents, grandchildren, uncles, aunts, nephews nieces and half-siblings.
- **Third-degree:** great-grandparents, great-grandchildren, great uncles/aunts and first cousins.
- **Fourth-degree:** great-great-grandparents, great-great-grandchildren and first cousins once-removed (children of the individual's first cousins).

### When Can an Employer Acquire Genetic Information?

In general, a Covered Entity cannot request, require or purchase genetic information of an individual or his or her family members. "Requesting" includes searching on the Internet, actively listening to third-party conversations, searching an individual's personal effects and making requests for information on an individual's current health status in a way that is likely to result in obtaining genetic information.

The prohibition on obtaining genetic information applies to medical examinations that are related to employment. The Covered Entity must tell health care providers not to collect genetic information, including family medical history, as part of a medical examination intended to determine the ability to perform a job.



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If the provider continues to require or request genetic information after being informed not to do so, the Covered Entity should take reasonable measures, including no longer using that provider's services.

There are some exceptions to this rule. A Covered Entity will not violate GINA if it obtains genetic information in a situation where the Covered Entity:

- Inadvertently requests or requires an individual's (or family member's) genetic information;
- Offers health or genetic services, including as part of a voluntary wellness program, as long as the individual is not required to provide genetic information to participate or receive a reward (for example, if a health risk assessment contains questions about genetic information, answering the questions must be optional and may not affect the individual's reward);
- Requests family medical history or information about a health condition to substantiate the need for leave under the FMLA or similar leave laws or policies;
- Acquires genetic information from commercially and publicly available documents, such as newspapers, magazines or books (with no intent of impermissibly obtaining information);
- Acquires genetic information for use in the genetic monitoring of biological effects of toxic substances in the workplace (as long as the monitoring is required by law, the individual has authorized the monitoring, and the Covered Entity receives only aggregate results);
- Conducts DNA analysis for law enforcement purposes as a forensic laboratory or for purposes of human remains identification, and requests or requires genetic information for quality control to detect sample contamination.

If a Covered Entity acquired genetic information in response to a lawful request for medical information (such as for documentation to support a request for leave or reasonable accommodation), the Covered Entity must have directed the individual or health care provider not to provide genetic information. The Covered Entity can use language provided in the final rule for this purpose. However, even if it does not use that language, the acquisition could still be inadvertent if the request was not likely to result in the Covered Entity obtaining genetic information.

Genetic information might also be received inadvertently if a manager or supervisor overhears a conversation, receives information during a casual conversation, is given the information without having asked for it, or sees information through a social media platform that he or she was given permission to access by the individual.

Note that a Covered Entity still may not discriminate against an individual because of genetic information obtained in these situations, and must protect this information as described below.

### **How Should Genetic Information be Protected?**

Covered Entities must keep any genetic information that they do acquire confidential. If the information is in writing, the Covered Entity is required to maintain that information on forms and in medical files that are separate from personnel files. This includes electronic forms and files. The information must be treated as a confidential medical record and may be maintained in the same file as confidential medical information that is subject to the Americans with Disabilities Act.

If genetic information was placed in a personnel file before Title II of GINA took effect on November 21, 2009, the information is not required to be removed, and the Covered Entity will not be in violation of the rules just because the information is in that file. However, the prohibitions on use or disclosure of the information do apply.



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If the Covered Entity receives genetic information orally, the information does not have to be reduced to writing. However, the information cannot be disclosed, unless specifically permitted by the final rule. Genetic information that is obtained through commercially and publicly available sources is not considered confidential. However, the information cannot be used to discriminate against the individual.

### **When Can Genetic Information be Disclosed?**

The final rule contains specific requirements for disclosing genetic information. A Covered Entity can disclose genetic information only in the following situations:

- To the employee or member (or family member if the family member is receiving the genetic services) about whom the information pertains to upon the employee or member's written request;
- To an occupational or other health researcher if the research is conducted according to applicable regulations;
- In response to a court order and with notice to the employee or member, if the court order was secured without his or her knowledge;
- To government officials investigating compliance with GINA;
- In support of an employee's compliance with the certification requirements of the Family and Medical Leave Act (or similar state law); or
- To a federal, state or local public health agency with regard to information about a contagious disease that presents an imminent risk of death or life-threatening illness, as long as the individual is notified of the disclosure.

However, note that the GINA regulations do not apply to the use or disclosure of genetic information that is protected health information subject to the HIPAA Privacy and Security Rules.

### **Do Employees Have to be Notified of their Rights?**

Yes, the final rules notes that Covered Entities must post notices in conspicuous places describing GINA's provisions. The EEOC has issued a revised poster that can be used for this purpose. For a copy of the poster, contact your F&A representative or visit <http://www1.eeoc.gov/employers/poster.cfm>.

### **How is the Final Rule Enforced?**

Enforcement of GINA's provisions is accomplished through the use of existing procedures for addressing other forms of employment discrimination. For most employees, the enforcement mechanisms and remedies of the Civil Rights Act of 1964 apply to GINA as well. Some government employees are protected by other specific anti-discrimination laws. The final rule also indicates that GINA provides for recovery of damages, including compensatory and punitive damages.

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