

Genetic Information Nondiscrimination Act of 2008 and EEOC's Proposed Regulation



**U.S. Equal Employment Opportunity Commission
Office of Legal Counsel**

Effective Date

- November 21, 2009
- EEOC will publish a final regulation before that date
- Watch www.eeoc.gov for further announcements

Coverage

- GINA applies to applicants and employees
- GINA applies to:
 - Employers covered under Title VII of the Civil Rights Act of 1964 (15 or more employees)
 - Federal executive branch agencies
 - State and local government employers

GINA and ADA

- **ADA prohibits discrimination on the basis of manifested conditions that meet the definition of disability.**
- **GINA prohibits discrimination based on genetic information and not on the basis of a manifested condition.**

GINA's Purposes

- **Enacted in response to developments in the field of genetics, the decoding of the human genome, and advances in genomic medicine.**
- **Congress was concerned that people were not taking advantage of genetic tests that could provide beneficial information because of concerns about discrimination by insurers or employers with access to their genetic information.**

Basic Rules Related to Employment

- Prohibits use of genetic information to discriminate in employment (absolute prohibition)
- Restricts the acquisition of genetic information by employers and other entities covered by GINA
- Requires that covered entities keep genetic information confidential, subject to limited exceptions

What is Genetic information?

Part 1

- Genetic Information means information about:
 1. An individual's **genetic tests** (1635.3(f))
 2. Genetic tests of **family members** (1635.3(a))
 3. The manifestation of a disease or disorder in family members (**family medical history** – 1635.3(b))
- (Citations refer to specific provision in the final regulations that addresses and provides further information about the particular point)

What is Genetic Information?

Part 2

- Genetic information includes:
 4. Request for or receipt of genetic services by an individual or family member
 - Meaning: genetic test, counseling, education
 5. Genetic information of a fetus carried by an individual or family member or of an embryo legally held by the individual or family member using an assisted reproductive technology.

Genetic Information Does NOT Include

- Information about an individual's or family member's age or gender
- The fact that an applicant/employee currently has a disease or disorder (manifested condition) – this individual would be protected by the ADA if the disease rises to the level of a disability.
- Remember: manifested condition in a family member = genetic information about applicant/employee

Acquisition of Genetic Information Prohibited

- **General Rule – 1635.8(a)**
 - Covered entities shall not request, require, or purchase genetic information about an applicant or employee
 - Six narrow exceptions to this prohibition
- These rules do not apply to one's personal doctor that is diagnosing or treating the individual.
 - These rules only apply to employers

1st Exception: No Liability for Inadvertent Acquisition - 1635.8(b)(1)

- Protects covered entity that unwittingly receives otherwise prohibited genetic information
- Examples of inadvertent acquisition – 1635.8(b)(1)(ii):
 - receipt of unsolicited email message that includes genetic information about an employee;
 - during a casual conversation or in response to a general inquiry, e.g., “How are you?”
 - documentation to support a request for reasonable accommodation

Inadvertent Acquisition Exception and Lawful Medical Inquiries & Exams

- ADA: Employers may conduct post-offer medical examinations/inquiries or fitness-for-duty examinations consistent with ADA requirements
- GINA:
 - Employer that asks for genetic information as part of an inquiry/medical exam will NOT be considered to have acquired the information inadvertently
 - Covered entities are prohibited from obtaining genetic information through any type of medical exam required of employees (i.e. post-offer and fitness for duty exams)

2. Permissible to Acquire Genetic Information Through Employer-Sponsored Health Services – 1635.8(b)(2)

- **Employer may request genetic information as part of a wellness program that meets specific requirements:**
 - Voluntary: employer must not require participation nor penalize employees who do not participate
 - Written request and knowing authorization
 - Information goes only to individual and health care provider
 - Employer gets information only in aggregate form

3. Permissible to Acquire Family Medical History under FMLA – 1635.8(b)(3)

- Individual requesting leave under FMLA or other similar local or State laws to care for family member with serious health condition will be required to provide family medical history
- Covered entity who receives this information does not violate GINA, but must keep it in separate medical file and treat it as a confidential medical record

4. Permissible to Acquire Genetic Information Through Commercially & Publicly Available Documents – 1635.8(b)(4)

- **Newspapers, periodicals, magazines, books**
- **Information obtained through electronic media such as television, movies, or the Internet (*discovery of genetic information is accidental when perusing these sources*)**
- **Exception #4 does not apply to searching medical databases, court records, or research databases available to scientists on a restricted basis.**

5. Permissible to Acquire Genetic Information Through Genetic Monitoring – 1635.8(b)(5)

- **Must meet certain requirements:**
 - Written notice and knowing, voluntary authorization (unless required by law or regulation)
 - Information goes only to individual and health care provider or certified genetic counselor involved in monitoring program
 - Covered entity gets information only in the aggregate

6. Permissible to Acquire for DNA Testing – 1635.8(b)(6)

- Applies only to employers that engage in DNA testing for law enforcement purposes as a forensic laboratory or for purposes of human remains identification**
- These employers may require genetic information from employees only to the extent that such genetic information is used for analysis of DNA markers for quality control to detect sample contamination**

Confidentiality - 1635.9

- Beginning Nov. 21, 2009, and thereafter, genetic information that an employer has must be kept confidential and placed in a separate medical file (ADA file is OK)
- Limited disclosure rules, some similar to ADA's rules, others unique to GINA – see 1635.9(b)