GINA
TITLE II FACT SHEET

Since the EEOC issued final regulations for Title II of the Genetic Information Nondiscrimination Act (GINA) in November of 2010, employers have been trying to wrap their arms around all of the far-reaching implications of the law. The information below provides some clarification of Title II provisions, as prescribed by the EEOC.

GINA TITLE II SUMMARY
Under Title II of GINA it is illegal to discriminate (as defined by Title VII of the Civil Rights Act of 1964) against employees or applicants because of genetic information. GINA prohibits the use of genetic information in making employment decisions, restricts employers and other entities covered by Title II of GINA from requesting, requiring or purchasing genetic information, and strictly limits the disclosure of genetic information.

COVERED ENTITIES
Employers;
Employment agencies;
Unions, and
Joint labor-management training and apprenticeship programs

GENETIC INFORMATION
Genetic information includes genetic tests and services on behalf of an individual or family member, and manifestations of a disease or disorder of an individual’s family members (family medical history).

Genetic Tests and Services - Genetic tests include any type of DNA analysis or test that detects genotypes, mutations, or chromosomal changes. Genetic services include any counseling, education and genetic information interpretation. Genetic tests include:

- BRCA testing and other diagnostic cancer testing;
- Prognostic testing for Huntington’s Disease;
- Screenings to determine risk of conditions such as cystic fibrosis or sickle cell anemia;
- Reproductive genetic testing and screening of all kinds, including amniocentesis, newborn screening and preimplantation genetic diagnosis;
- Pharmacogenetics testing, and
- DNA testing for ancestry or familial/paternity relationships.

Manifestation of a disease or disorder of an individual’s family members - Does not include an individual’s own manifestation of disease or disorder. Employers are not barred from using, acquiring or disclosing medical information about an individual’s “manifested” disease, disorder, or pathological condition, even when such disease or disorder has a genetic component. However, according to the EEOC, genetic information alone is not enough to qualify as a “manifest” disease or disorder - other signs or symptoms must be present, as well. For instance, an employee who has tested positive for Huntington’s disease, is not considered to have a “manifest” disease until he or she starts displaying symptoms.
FAMILY MEMBER

Under GINA a family member includes all relatives up to the 4th degree, including a fetus or embryo carried by an individual or by a pregnant woman who is a family member of the individual and any embryo legally held by the individual or family member using an assisted reproductive technology (surrogate pregnancy). Family member also includes people who are or who become related to an individual through marriage, birth, adoption or placement for adoption.

First Degree - the individual's children, siblings, and parents
Second Degree - grandparents, grandchildren, uncles, aunts, nephews, nieces, and half-siblings
Third Degree - great-grandparents, great grandchildren, great uncles, great aunts, and first cousins
Fourth Degree - great grandparents and first cousins once removed (the children of a first cousin)

SIX EXCEPTIONS TO RULES AGAINST ACQUIRING GENETIC INFORMATION

1. **Inadvertent acquisition of genetic information** – An employer does not violate the law by inadvertently obtaining genetic information through casual conversation with employees or inadvertently overhearing an employee talking about a family member’s illness. HOWEVER, the employer must NOT ask follow-up questions that are “probing” in nature or engage in any act that is “likely to result” in the acquisition of genetic information, e.g., sharing information about an acquaintance outside of work who has or had the same disease or disorder.

2. **FMLA Leave for Family Care** – Family medical history may be acquired as part of the certification process where an employee is requesting FMLA leave to care for a family member with a serious health condition. **THIS IS THE ONLY SITUATION IN WHICH FAMILY MEDICAL HISTORY MAY BE ACQUIRED.** HOWEVER, certification requests should be limited in scope to only that information which is necessary to make a determination regarding eligibility for leave.

3. **Wellness Program with a Health Risk Assessment (HRA) that is NOT linked to the health plan** – In order for an HRA to qualify under Title II of GINA, it must not be limited to just those employees enrolled in the health plan, and employee incentives or benefits related to the program, must not be conditioned upon the provision of genetic information. Under Title II, HRAs can only request family health history if the following requirements are met:
   - The request for family health history is made as part of a wellness program or other health or genetic services offered by the employer;
   - The employee provides prior, knowing, voluntary and written authorization;
   - Any individually identifiable genetic information is provided only to the employee and a the licensed health care professional or board certified genetic counselor involved in the program, and
   - The employer may only obtain aggregated genetic information.

Detailed information regarding the impact of Title I and Title II of GINA on HRAs can be found at [http://www.associatedfinancialgroup.com/fileDownloads/NewsAndAnnouncements/GINA.pdf](http://www.associatedfinancialgroup.com/fileDownloads/NewsAndAnnouncements/GINA.pdf)
4. **Publicly Available Information** – Genetic information may be obtained from commercially and publicly available sources, such as newspapers, magazines, periodicals and books, as long as the employer is not searching those sources with the intent of finding genetic information or accessing sources from which they are likely to acquire genetic information (CaringBridge website). Also excluded from “publicly available sources” are networking sites and online media sources which require permission to access from a specific individual (private MySpace/Facebook pages).

5. **Toxic workplace substances monitoring** – Employers may acquire aggregate genetic information through a genetic monitoring program that monitors the biological effects of toxic substances in the workplace where:
   - The employer provides written notice of testing;
   - The employee provides prior, knowing, voluntary and written authorizations;
   - Testing is required by law, and
   - Testing is conducted in compliance with the OSHA, Federal Mine Safety and Health Act and Atomic Energy Act regulations

6. **Law enforcement purposes** – Employers may request genetic information of employees to maintain quality control of samples in a forensic lab or for purposes of identifying human remains.

**MEDICAL INFORMATION REQUESTS**

If an employer acquires genetic information as a result of a lawful request for medical certification, as permitted by FMLA or ADA, the acquisition of such information can be considered “inadvertent” **ONLY IF** the employer directs (preferably in writing) the individual or health care provider from whom it requested medical information **not to provide genetic information**. The EEOC has provided sample language that employers can use in a request for medical information that will satisfy this notice requirement. [Notice to Health Care Provider Regarding The Genetic Information Nondiscrimination Act](#).

**GENETIC DISCLOSURE EXCEPTIONS**

An employer may disclose **relevant** genetic information about an applicant, employee or member to government officials investigating compliance with Title II of GINA and in response to a court order.

**CONSEQUENCES FOR TITLE II GINA VIOLATIONS**

The same remedies available under Title VII are available to employees under Title II of GINA. This includes reinstatement, hiring, promotion, back pay, injunctive relief, compensatory and punitive damages, and attorneys’ fees and costs. The cap on combined compensatory and punitive damages (excluding past monetary losses) ranges from $50,000.00 for employers with 15 to 100 employees, to $300,000.00 for employers with more than 500 employees.
"The Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits employers and other entities covered by GINA Title II from requesting or requiring genetic information of an individual or family member of the individual, except as specifically allowed by this law. To comply with this law, we are asking that you not provide any genetic information when responding to this request for medical information. 'Genetic information' as defined by GINA, includes an individual's family medical history, the results of an individual's or family member's genetic tests, the fact that an individual or an individual's family member sought or received genetic services, and genetic information of a fetus carried by an individual or an individual's family member or an embryo lawfully held by an individual or family member receiving assistive reproductive services."