What is GINA?

GINA is the Genetic Information Nondiscrimination Act of 2008. In pertinent part, GINA forbids discrimination on the basis of genetic information when it comes to any aspect of employment, including hiring, firing, pay, job assignments, promotions, layoffs, training, fringe benefits, or any other term or condition of employment. An employer may never use genetic information to make an employment decision because genetic information doesn’t tell the employer anything about someone’s current ability to work.

Why is this important to me?

You should read this carefully because “genetic information” includes knowledge of an individual’s family medical history, knowledge any employee may easily acquire in a casual conversation and that supervisors may acquire when acting on leave requests. In addition, if you hold a position that may involve seeking information about an individual’s current health status, you need to be particularly vigilant that you inform the health provider not to provide you with any genetic information.

What law and regulations have been issued on genetic information?

- The Genetic Information and Nondiscrimination Act of 2008 (GINA), Public Law 110-233, codified at 42 U.S.C. §2000ff et seq., was enacted because new knowledge about genetics gives rise to the potential misuse of genetic information to discriminate in health insurance and employment. GINA’s Title I pertains to health insurance and Title II pertains to employment.

- The Equal Employment Opportunity Commission (EEOC) published final regulations for Title II of GINA, 29 CFR Part 1635, on November 9, 2010 in the Federal Register and stated the regulations are effective January 10, 2011.

What are the major requirements of GINA that affect Federal employment?

- GINA prohibits the use of genetic information in employment decision-making, restricts employers and other entities from requesting genetic information, requires that such information be maintained as confidential medical information, and strictly limits disclosing genetic information. Note: It will be very easy to run afoul of GINA’s very broad definition of a request, but liability is avoidable, as explained below.
Federal employees or applicants have the right to file an employment discrimination complaint if they believe their genetic information was acquired, used, or disclosed in violation of the regulations. The same remedies available under Title VII of the Civil Rights Act of 1964 (Title VII) are available under Title II of GINA. An aggrieved individual may seek reinstatement, hiring, promotion, back pay, injunctive relief, monetary damages (including compensatory damages), and attorneys’ fees and costs. Like Title VII, GINA prohibits harassment and retaliation against persons who oppose employment practices made unlawful by GINA (for example, by refusing to provide genetic information) or who participate in a proceeding, investigation, or hearing under GINA (such as by filing a complaint).

What is genetic information?

- **Genetic information** includes family medical history; the genetic tests of an individual and the individual's family; an individual's request for or receipt of genetic services or participation in clinical research that includes genetic services; and the genetic information of a fetus carried by an individual or by a pregnant woman who is a family member and the genetic information of any legally held embryo.

- **Family member** means a person who is a dependent of the individual as the result of marriage, birth, adoption, or placement for adoption, or a relative of the first-, second-, third-, or fourth-degree, which ranges all the way to great-great-grandparents; great-great-grandchildren, and first cousins once-removed (i.e., the children of the individual's first cousins).

What actions are prohibited by GINA?

- Disclosing genetic information about an individual except for the work-related reasons provided in the regulations, even when the information is initially disclosed by the individual or is inadvertently acquired.

- Discriminating against an individual on the basis of genetic information in regard to hiring, discharge, compensation, terms, conditions, or privileges of employment.

- Limiting, segregating, classifying, or failing to refer for employment or employment opportunities or otherwise affecting the status of the individual as an employee because of genetic information; however, there is an exception if a covered entity is required to limit or restrict job duties based on genetic information based on a law or regulation mandating genetic monitoring. For example, an employer could not reassign someone whom it learned had a family medical history of heart disease from a job it believed would be too stressful and might eventually lead to heart-related problems for the employee. However, an employer may limit or restrict an employee's job duties based on genetic
information if required to do so by a law or regulation mandating genetic monitoring such as regulations administered by the Occupational and Safety Health Administration (OSHA), the Mine Safety and Health Administration or other workplace health and safety laws and regulations.

- Retaliating against an individual who has opposed an act or practice or participated in any manner in an investigation, proceeding, or hearing under Title II of GINA.

- Requesting, requiring, or purchasing genetic information of an individual or a family member unless the action falls within an exception specifically provided in the regulations.

What constitutes a request for genetic information?

- Making requests for information about an individual's current health status in a way that is likely to result in obtaining genetic information.

- Conducting an Internet search on an individual in a way that is likely to result in a covered entity obtaining genetic information.

- Actively listening to third-party conversations or searching an individual's personal effects for the purpose of obtaining genetic information.

How can liability under GINA be avoided when requesting medical information from employees on such matters as absence without leave determinations, reasonable accommodation requests, and Family and Medical Leave Act (FMLA) requests?

Because an employee must demonstrate that he or she is entitled to leave to care for a family member with a medical condition under the FMLA, employer policies may require the employee to provide family medical history (i.e. information about the manifestation of a disease or disorder in the family member) to the employer. Without this exception, requiring family medical history under these circumstances would violate GINA.

Bear in mind that an employer’s request for documentation supporting a request for reasonable accommodation is lawful only when the disability and/or the need for accommodation is not obvious. The employer should only request sufficient documentation to establish that an individual has a disability and needs a reasonable accommodation.

When an employer makes a request for health-related information (e.g., to support an employee’s request for reasonable accommodation or a request for sick leave), it should warn the employee and/or health care provider from whom it requested the information not to provide genetic information. The regulations provide “safe harbor”
language for medical information requests and, if this language is included, specify that any genetic information acquired would be viewed as inadvertently obtained. Agency requests for medical information should include language such as the following (which is taken verbatim from the regulations):

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.

What does it mean to acquire genetic information “inadvertently”?

The general rule against requesting genetic information does not apply in situations where the information was acquired inadvertently, through overhearing a conversation or in response to a general health inquiry, such as “How are you?” or “Did they catch it early?” This latter exception does not apply when the employer follows up with questions that are probing in nature. Therefore, while supervisors may express concern about their employees, supervisors must take care not to encourage employees to provide detailed information about the medical status of any employee or family members of an employee.

What about liability under programs focused on genetic information?

A covered entity also may obtain genetic information: as part of health or genetic services, including wellness programs, if the information is obtained on a voluntary basis and certain specific requirements are met; for a genetic monitoring program that monitors the biological effects of toxic substances, if the program is voluntary or required by law; and from employees in certain instances for law enforcement purposes.

How must genetic information which is acquired be handled?

Any genetic information that is acquired must be kept confidential. Accordingly, supervisors should not share with others any genetic information about employees whether or not it was originally inadvertently acquired. Any genetic information must be kept in a separate file from an employee’s personnel file but can be in the same file with documents protected under the Rehabilitation Act.
What are the remedial and enforcement provisions of GINA?

Federal employees and applicants are covered by the GINA regulations, and they may use the Federal EEO complaint process when they believe the law has been violated, as provided by 29 CFR §§1635.2(c)(5) and 1635.10(a)(5). An individual may contact an EEO Counselor about an alleged violation of the GINA regulations, and if the matter is not resolved, may file a formal complaint of discrimination based on genetic information. Reinstatement, hiring, back pay, compensatory damages, attorney’s fees, and other appropriate remedies may be ordered.

This GINA FAQ summarizes some of the important matters covered by the regulations but is not intended to describe every significant point. If you have additional questions, please contact your Human Resources or EEO Office.