

CLIENT ALERT: EEOC Regulations Provide Guidance on the Many Issues Raised by GINA

In November 2010, the Equal Employment Opportunity Commission (“EEOC”) issued final regulations providing guidance on Title II of the Genetic Information Nondiscrimination Act (“GINA”). This alert highlights the important ways in which the regulations clarify aspects of GINA that have emerged as areas of particular confusion and concern for employers. The full regulations can be found [here](#). (This alert addresses Title II of GINA, but not Title I, which prohibits discrimination based on genetic information in health coverage.)

Who does GINA cover?

Title II applies to private employers and state and local government employers with 15 or more employees, employment agencies, labor unions, joint labor-management training programs, federal executive branch agencies and the Executive Office of the President (collectively referred to as “covered entities”). The regulations reiterate that Title II’s use of “employee” also encompasses applicants for employment and former employees in addition to present employees.

What does GINA prohibit?

Unlawful uses of genetic information

Generally, GINA prohibits covered entities from discriminating in any way, including with regard to health benefits, against employees based on genetic information. It also prohibits covered entities from limiting, segregating, or classifying employees because of genetic information. As an example, the regulations offer the situation of an employee with a family history of heart disease. The employer cannot reassign that employee because it believes the employee’s current job is too stressful and might lead to heart problems based on the employee’s family medical history.

Further, GINA incorporates the same prohibition on retaliation as Title VII, protecting an employee from retaliation for opposing any act unlawful under

GINA, filing a charge of discrimination or helping someone else do so, or giving testimony in connection with a charge.

GINA also specifically prohibits employment agencies, labor organizations, and apprenticeship or other training programs from causing an employer to discriminate on the basis of genetic information. Similarly, an employer cannot use another covered entity acting as its agent as a conduit for discrimination. For example, an employer cannot instruct an employment agency to ask for genetic information or instruct that applicants be screened out based on family medical histories.

Unlawful acquisition of genetic information

GINA prohibits covered entities from requesting, requiring, or purchasing genetic information. The employer does not need to have a deliberate intent to acquire genetic information to violate GINA. To prove a violation, it is sufficient for an employer to engage in an activity with a “heightened risk” of leading to the acquisition of genetic information. Specific examples of prohibited acquisition listed in the regulations include searching the internet in a way likely to obtain genetic information, searching through an individual’s personal belongings, and making inquiries into a person’s current health condition in a way that is likely to result in obtaining genetic information.

What is genetic information?

Generally, under GINA, genetic information includes:

- Information about an individual’s genetic tests
- Information about the genetic tests of an individual’s family member
- Requests for and receipt of genetic services by an individual or an individual’s family member
- Genetic information about a fetus carried by an individual or an individual’s family member or of an embryo legally held by an individual or an individual’s family member using assisted reproductive technology

Employers must appreciate how broadly this definition sweeps. The regulations make clear that “genetic information” includes information that might not appear “genetic” at first blush. A prime example is information about an employee’s family medical history. For example, an employer might know that breast cancer runs in a particular employee’s family. That

information is “genetic information” for purposes of GINA because it reveals that the employee likely has a genetic predisposition to developing breast cancer.

What is a genetic test?

The regulations have elaborated on the term “genetic test” as it is used in GINA’s definition of genetic information. Generally, tests that are used to determine if an individual has a genetic disposition to a disease are “genetic tests” under GINA. Examples include testing for the genetic variants associated with breast cancer and Huntington’s disease. Also included are tests to determine the risk of conditions like cystic fibrosis and sickle cell anemia in potential future offspring and tests to establish family relationships (e.g. paternity tests). Tests that are used to determine the actual present manifestation of a particular condition, and not an individual’s genetic predisposition, are not “genetic tests.” The regulations list tests for HIV, cholesterol, and the presence of alcohol or drugs as examples of tests that are not genetic tests under GINA.

This is a difficult but important distinction to grasp – GINA only protects individuals from being discriminated against on the basis of genetic information that reveals the potential for the manifestation of a disease in the future. It does not protect against discrimination for present manifestations of conditions (although that conduct could fall under a different statutory scheme like the Americans with Disabilities Act (the “ADA”) or similar state law). To illustrate, if an employer discriminated against an employee because of her family history of breast cancer, that conduct would fall under GINA. If, on the other hand, the employer discriminated against the employee for reasons related to her own breast cancer, that conduct would not fall under GINA.

Who is a family member?

As seen above, family medical history is an important area of information covered by GINA. “Family member” as used by GINA with respect to any individual means a person who is a dependent of that individual as the result of marriage, birth, adoption, or placement for adoption OR the individual’s relatives, or the individual’s dependent’s relatives, to the fourth degree. The degrees of familial relationship are 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 children of first cousins

Are there any exceptions?

The above prohibitions on a covered entity's use of genetic information are absolute. There are, however, six narrow exceptions to GINA's acquisition prohibition:

Inadvertent acquisition

The regulations address the practical issues posed by typical workplace conversation around the "water cooler." An employer does not violate GINA when it receives genetic information by inadvertently overhearing an employee conversation, in response to an inquiry about an employee's wellbeing, as the result of an unsolicited communication from an employee, or accidentally through a social-media platform that the supervisor had received permission from the individual to access. For example, it would not be a violation of GINA if, in response to a supervisor's question about whether he had a nice weekend, an employee responded that his father had been diagnosed with prostate cancer. It would also not be a violation if a supervisor who happened to be Facebook friends with an employee viewed a post that indicated an employee's mother had breast cancer.

Lawful requests

When obtaining health information as part of a lawful request for medical information (e.g. under FMLA or ADA), employers will not violate GINA if they inadvertently acquire genetic information only if they specifically direct the individual and/or healthcare provider not to provide genetic information and their request is not otherwise likely to result in obtaining genetic information. GINA provides the following specific language that employers can elect to use when communicating with healthcare providers to ensure they fall within this safe harbor:

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.

Family Medical Leave

GINA makes a specific exception to the general prohibition on acquiring family medical information for purposes of Family and Medical Leave Act (“FMLA”) compliance (or a similar leave process under state or local law or employer policies). Employers do not violate GINA by requesting family medical history in the context of certifying an employee’s FMLA leave to care for a sick family member. Nor does the employer violate GINA by acquiring information about an employee’s manifested condition if the employer happens to employ a family member of the sick employee.

Health or genetic services

GINA permits an employer to acquire genetic information as part of a voluntary health, genetic-services, or wellness program. The regulations specify that employers may not offer financial incentives for providing genetic information but may offer an incentive where the provision of genetic information is totally voluntary and the employer makes clear that the employee does not have to provide any genetic information in order to receive the incentive.

Publicly Available

An employer will not violate GINA by acquiring genetic information from a publicly available source. Publicly available generally means a source that can be accessed without a membership or username/password. Employers must

bear in mind, however, that an employer will still have violated GINA if, for example, it searches the internet in a way that is likely to lead to genetic information, even if that information turns up in a publicly available source.

Genetic Monitoring

Although this issue is unlikely to arise in many workplaces, it bears mentioning that under certain conditions spelled out in the regulations, an employer can engage in genetic monitoring of the biological effects of toxic substances in the workplace. An employer cannot retaliate or otherwise discriminate against an employee who refuses to participate in genetic monitoring that is not specifically required by law.

Law Enforcement

GINA permits forensic laboratories to collect employee genetic information in certain limited circumstances to the extent that the information is needed to detect sample contamination.

How should an employer maintain employee genetic information?

With some limited disclosure exceptions, employers must maintain genetic information apart from an employee's personnel file and in the same manner as required by the ADA. Genetic information that the employer acquires verbally does not need to be reduced to writing but is subject to the same limitations on disclosure. While GINA's confidentiality requirements do not apply to genetic information that is acquired from publicly available sources, employers are nonetheless prohibited from using that information to discriminate against an employee.

As is typically the case with workplace issues, it is impossible to anticipate each of the countless ways in which GINA might be implicated on a day-to-day basis. For assistance with applying GINA to your particular circumstances, please contact your M&J attorney.

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