EEOC Issues Final GINA Regulations

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On November 9, 2010, the Equal Employment Opportunity Commission issued the long-awaited final regulations under Title II of the Genetic Information Nondiscrimination Act ("GINA"). Title II of GINA, which went into effect in November 2009, prohibits using genetic information in making employment decisions, restricts acquisition of genetic information by employers and strictly limits its disclosure. It is critical for employers to avoid violating GINA, particularly when making otherwise proper requests for employee medical information.

Congress enacted GINA in 2008 in response to concerns that patients would decline to take advantage of the increasing availability of genetic testing out of concern that they could lose their jobs or health insurance if such tests revealed adverse information. As Congress noted, "New knowledge about genetics may allow for the development of better therapies that are more effective against disease or have fewer side effects than current treatments. These advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment."

Title II of GINA prohibits employment discrimination based on genetic information, and restricts the acquisition and disclosure of genetic information. Genetic information includes information about individuals' genetic tests and the tests of their family members; family medical history; requests for and receipt of genetic services by an individual or a family member; and genetic information about a fetus carried by an individual or family member or of an embryo legally held by the individual or family member using assisted reproductive technology.

Proposed regulations were issued in March 2009, and comments were requested by the EEOC. The final rules were issued following the receipt of comments.

The final regulations provide examples of genetic tests; more fully explain GINA's prohibition against requesting, requiring, or purchasing genetic information; provide model language employers can use when requesting medical information from employees to avoid acquiring genetic information; and describe how

GINA applies to genetic information obtained via electronic media, including websites and social networking sites.

The Commission has also issued two question-and-answer documents on the final GINA regulations, one of which is aimed at helping small businesses comply with the law. Links to the regulations and to the questions-and-answers are on EEOC's website. Although the question-and-answer documents are geared to small employers, it is a valuable resource for all employers, as it provides a helpful overview of GINA's requirements and its impact on employers generally.

Summary of Key Provisions

Purpose

The EEOC clarified three major points concerning Title II's purpose: (1) whether intent to acquire genetic information is required in order to establish a violation, (2) what is the scope of violative acquisitions and (3) to what status of an individual does the law apply.

Intent. In response to comments that disagreed with the characterization of Title II as prohibiting the "deliberate acquisition" of genetic information, the final rule provides that no specific intent to acquire genetic information is required in order to establish a violation. In reaching this conclusion, the EEOC agreed with comments that a covered entity violates GINA by engaging in acts that present a heightened risk of acquiring genetic information, even without a specific intention to do so, such as when they fail to inform an individual from whom they have requested documentation about a manifested disease or disorder not to provide genetic information or when they access sources of information (e.g., certain types of databases, Web sites, or social networking sites) that are likely to contain genetic information about individuals.

Scope of Violative Acquisitions. The Commission also explained the scope of acquisitions that violate Title II, specifically clarifying that not every acquisition of genetic information violates GINA, and, accordingly, the regulations now simply indicate that Title II of GINA restricts requesting, requiring, or purchasing genetic information.

Status of Individual. The final rule makes clear that it does not apply to actions of a covered entity that do not pertain to an individual's status as an employee, member of a labor organization, or participant in an apprenticeship program.

What Is a Request For Genetic Information?

GINA generally prohibits employers from requesting, requiring, or purchasing" genetic information from an individual or a family member of the individual. The final regulations define the term "request" broadly, explaining that it "includes 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; and making requests for information about an individual's current health status in a way that is likely to result in a covered entity obtaining genetic information."

Passive Acquisitions/Inadvertent Disclosure

Notwithstanding this broad definition, the regulations also recognize that Congress intended certain "passive acquisitions" of genetic information to be exceptions to the rule prohibiting acquisition. In this regard, the regulations provide that a covered entity that inadvertently requests or requires family medical history from an individual does not violate GINA. The EEOC notes that Congress intended this exception to address what it called the "water cooler problem" in which an employer unwittingly receives otherwise prohibited genetic information in the form of family medical history through casual conversations with an employee or by overhearing conversations among co-workers. Although the language of this exception in GINA specifically refers to family medical history, the Commission believes that it is consistent with Congress's intent to extend the exception to any genetic information that an employer inadvertently acquires.

Requests For Medical Information

A significant number of comments expressing concern about GINA's application to a covered entity's request for medical information that results in the receipt of genetic information that was not requested. Civil rights groups, groups promoting genetic research, and others argued that covered entities will obtain a great deal of genetic information through general requests for medical information if they are not required to affirmatively indicate that genetic information should not be provided. In response to these comments and to facilitate compliance with the law, the EEOC added language to the final rule indicating that when a covered entity warns anyone from whom it requests health-related information not to provide genetic information, the covered entity may take advantage of a specified exception if it nevertheless receives genetic information. This "safe harbor" exception provides that any receipt of genetic information in response to a lawful request for medical information will be deemed inadvertent and not in violation of GINA if the request contained such a warning. The regulations provide language that can be used to provide such notice.

Family and Medical Leave Act

GINA recognizes that individuals requesting leave to care for a seriously ill family member under the Family and Medical Leave Act (FMLA) or similar state or local law will be required to provide family medical history (for example, when completing the certification form required by the FMLA)[1]. A covered entity that receives family medical history under these circumstances would not violate GINA. This exception is needed because, unlike the situations discussed under the inadvertent acquisition exception, the receipt of genetic information in these circumstances is not inadvertent. By asking the employee to provide the information required by the FMLA certification form or similar state or local laws when seeking leave to care for a seriously ill family member, a covered entity is requesting family medical history from the employee. It is important to note that family medical history received from individuals requesting leave pursuant to the FMLA, similar state or local laws, or company policies, is still subject to GINA's confidentiality requirements and must be placed in a separate medical file and treated as a confidential medical record.

Wellness Programs

GINA permits covered entities to acquire genetic information where health or genetic services are offered by the employer, including such services offered as part of a wellness program, if the covered entity meets specific requirements, including a requirement that participation in the program be knowing and voluntary. Comments to the proposed regulations raised the issue of whether "voluntary" participation included situations where an employer offers financial or other incentives to participate in the program.

The EEOC weighed various approaches and concluded that after balancing the potential benefits of health and genetic services offered to employees on a voluntary basis, including wellness programs with the need to construe exceptions to the prohibition of acquisition of genetic information in a manner appropriately tailored to their specific purposes, covered entities may offer certain kinds of financial inducements to encourage participation in health or genetic services under certain circumstances, but they may not offer an inducement for individuals to provide genetic information. As a result, the Commission concluded that it would not violate Title II of GINA for a covered entity to offer individuals an inducement for completing a health risk assessment that includes questions about family medical history or other genetic information, as long as the covered entity specifically identifies those questions and makes clear, in language reasonably likely to be understood by those completing the health risk assessment, that the individual need not answer the questions that request genetic information in order to receive the inducement.

How Nossaman Can Help

GINA and the final regulations impose new compliance burdens on employers. Nossaman attorneys are available to assist in such matters as evaluating employer policies and controls to insure against the improper receipt of genetic information, preparing the "safe harbor" notices to be included in lawful requests for medical information and assistance in the design of compliant wellness programs.

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[1] It should be noted that under California law, an employer is not permitted to request medical information when considering a request for leave under FMLA and its California counterpart, the California Family Rights Act.