

Beware of GINA By Tammy L. Baker, Frank Alvarez and Michael J. Soltis

Genetic Information Includes Much More Than You Thought, And It Will Probably Affect Your Organization

The Genetic Information Nondiscrimination Act of 2008 (GINA).

Whether the searching, actively listening or asking for information was likely to result in obtaining genetic information is likely going to be a fact specific inquiry.

Exceptions

There are exceptions to the general prohibition on acquiring genetic information, including:

- *Where an employer “inadvertently” requests or requires genetic information of the individual or family member;*
- *Where an employer offers health or genetic services, including such services offered as part of a voluntary wellness program;*
- *Where an employer requests family medical history to comply with the certification provisions of family and medical leave laws;*
- *Where an employer requests family medical history to comply with a policy that permits the use of leave to care for a sick family member, and requires supporting documentation to substantiate the need for leave;*
- *Where an employer acquires genetic information from documents that are commercially and publicly available, but not including certain restricted medical and research databases;*
- *Where an employer acquires genetic information for use in the genetic monitoring of biological effects of toxic substances in the workplace, provided the employer meets specific notice requirements;*
- *Where an employer conducts DNA analysis for law enforcement purposes as a forensic laboratory or for purposes of human remains identification and requests or requires genetic information of its employees for these limited purposes;*
- *Where an employer requests, requires or purchases information about a manifested disease, disorder, or pathological condition of an employee whose family member is an employee for the same employer; and*
- *Where an employer requests, requires or purchases genetic information or information about a manifested disease, disorder, or pathological condition of an individual’s family member who is receiving health or genetic services on a voluntary basis.*

These exceptions are available to an employer who does not act with the intent of obtaining genetic information. The most challenging is likely determining the parameters of the “inadvertent” acquisition exception. Acquisition of genetic information in response to a lawful request for medical information will not generally be inadvertent unless the employer directs the entity from whom it requested such information (in writing, or verbally, where the employer does not typically make requests for medical information in writing) not to provide genetic information.

When an employer lawfully requests medical information and receives genetic information in response, such receipt will be deemed inadvertent if an employer uses “safe harbor” language such as this:

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. Absent such notice, an employer may still establish “inadvertent acquisition” if its request for medical information was not “likely to result in ...obtaining-genetic information” (e.g., where the response to a narrowly tailored request for information is overly broad).

These “inadvertent acquisition” rules apply, for example, where an employer requests:

- *documentation to support a lawful request for reasonable accommodation;*
- *medical information as legally required, authorized, or permitted, such as where an employee requests leave under the Family and Medical Leave Act (FMLA) to attend to the employee’s own serious health condition or where an employee complies with the FMLA’s employee return to work certification requirements; or*
- *documentation to support a request for leave not required by law as long as the documentation required otherwise complies with the requirements of the ADA and other laws limiting an employer’s access to medical information.*

The “inadvertent acquisition” exception also applies, for example, where a manager or supervisor learns genetic information about an individual by overhearing a conversation between the individual and others, so long as the manager or supervisor was not “actively listening” or learns genetic information about an individual by receiving it from the individual or others during a casual conversation, including in response to an ordinary expression of concern that is the subject of the conversation. For example, the exception applies when a supervisor receives family medical history directly from an individual following a general health inquiry or a question as to whether the individual has a manifested condition. According to the regulations, questions such as “how are you?” or “did they catch it early?” asked of an employee who was just diagnosed with cancer, or a casual question concerning the general well-being of a parent or child, would not violate GINA. However, employers are prohibited from asking more probing questions, such as whether other family members have the condition or whether the individual has been tested for the condition, because the employer should know that these questions are likely to result in the acquisition of genetic information. The exception also applies where the manager or supervisor learns genetic information from the individual or others without having solicited or sought the information (e.g., where a manager or supervisor receives an unsolicited email about the health of an employee’s family member from a co-worker) or inadvertently learns genetic information from a social media platform which he or she was given permission to access by the creator of the profile at issue (e.g., a supervisor and employee are connected on a social networking site and the employee provides family medical history on his page).

Health and Genetic Services, including Voluntary Wellness Programs

Another exception to the general prohibition against acquiring genetic information, including family medical history, is when this information is requested as part of an employer’s “health or genetic services, including such services offered as part of a voluntary wellness program.” This exception applies if (1) the employee provides genetic information voluntarily, and provides prior, voluntary written authorization, written in understandable language, which describes the genetic information that will be obtained, the general purposes for which it will be used, and the restrictions on its disclosure; (2) individually identifiable genetic information is provided only to the individual (or family member receiving genetic services) and the licensed health care professionals or board certified genetic counselors providing such services, and is not accessible to anyone else in the workplace and (3) individually identifiable genetic information is not disclosed to the employer except in aggregate terms. An employer may not offer a financial inducement for individuals to provide genetic information but may do so for completion of health risk assessments (HRA) that include questions about family medical history or other genetic information, if it makes clear that the inducement will be provided regardless of whether the participant answers questions regarding genetic information. For example, an employer may offer \$150 to those who complete a 100 question HRA, the last 20 of which concern family medical history and other genetic information, if the instructions make clear that the inducement will be granted for responding to the first 80 questions only. An employer may offer financial inducements to individuals who have voluntarily provided genetic information (e.g., family medical history) who are at increased risk of acquiring a health condition to participate in disease management or other programs that promote healthy lifestyles, and/or to meet particular health goals if these programs are also offered to individuals with current health conditions and/or to those whose lifestyle choices put them at increased risk of developing a condition. For example, an employer may offer employees who voluntarily disclose a family medical history of diabetes, heart disease, or high blood pressure on a lawful HRA, and those who have a current diagnosis of at least one of these conditions, \$150 to participate in a wellness program designed to encourage weight loss and a healthy lifestyle, and may offer

additional inducements for achieving certain health outcomes, such as lowering blood pressure, glucose, and cholesterol levels, or for losing weight. (Not that GINA does not limit the rights or protections of an individual under the ADA or under HIPAA.)

Also, employers who offer wellness programs must still consider whether Title I of GINA, which is not addressed in this article, covers group health insurance plans and potentially restricts the use of financial incentives to obtain genetic information in wellness programs.)

Confidentiality and Posting Requirements

Like the ADA, GINA requires employers to keep records containing genetic information on separate forms and in separate medical files and to treat them as confidential medical records. Genetic information placed in an employee's personnel file before November 21, 2009, does not need to be removed although the prohibitions against disclosing or using genetic information apply to all genetic information regardless of when it was obtained. Although an employer may disclose genetic information in response to a court order or subpoena, the employer must narrowly limit this disclosure to only the genetic information expressly authorized by the order. If the order was secured without the knowledge of the individual to whom the information refers, the employer must inform the individual of the court order and any genetic information that was disclosed pursuant to the order. The regulations do not authorize an employer to disclose such information in response to a discovery request.

Steps Towards Complying with GINA

There are a few steps employers can take to ensure that they are complying with GINA:

- *Educate your human resources team and managers and supervisors about GINA's definitions and prohibitions.*
- *Modify employee handbook by including a general provision that states that the company does not discriminate based on genetic information or family medical history.*
- *Include a provision in your leave policy asking employees not to provide genetic information or family medical history, except as needed to support a request for leave.*
- *Use the safe harbor notice whenever you request medical information from an employee's health care provider.*
- *Ensure that healthcare providers on whom the company relies for employee medical do not take family medical history, and remind them that they should not provide you with genetic information or family medical history. This applies to fitness for duty exams, ADA accommodation inquiries, and FMLA certifications relating to an employee's leave.*
- *Revise forms used in wellness programs to separate the requests for genetic information from requests for other information, and specify that the participant is not obligated to provide the genetic information.*
- *Maintain medical files that are separate from personnel files.*
- *Avoid "probing questions" and eavesdropping.*
- *Do not conduct Internet searches on applicants or employees.*

Tammy L. Baker, (bakert@jacksonlewis.com), Frank Alvarez and Michael J. Soltis are all Jackson Lewis Partners and members of Jackson Lewis' Disability, Leave and Health Management Practice Group. No representation is made that the quality of legal services to be performed is greater than the quality of legal services performed by other lawyers.