Provided by Clarke & Company Benefits, LLC

GINA Q&As for Employers

The Genetic Information Nondiscrimination Act of 2008 (GINA) generally prohibits employers from discriminating against employees or applicants based on their genetic information. More specifically, GINA:

- ✓ Prohibits the use of genetic information when making employment decisions;
- ✓ Restricts employers and other entities covered by Title II of GINA (employment agencies, labor organizations and joint labor-management training and apprenticeship programs) from requesting, requiring or purchasing genetic information; and
- ✓ Strictly limits the disclosure of genetic information.

To assist employers with GINA compliance, the Equal Employment Opportunity Commission (EEOC) issued frequently asked questions (FAQs) regarding GINA. This Compliance Overview includes select FAQs from the EEOC.

LINKS AND RESOURCES

- EEOC's November 2010 final rule on GINA's employment protections
- EEOC's web page on GINA compliance
- EEOC's final rule issued on May 17, 2016, regarding offering a limited incentive for an employee's spouse to provide certain health information as part of a wellness program

HIGHLIGHTS

GENERAL PROHIBITIONS

- It is illegal to discriminate against employees or applicants because of genetic information.
- GINA prohibits covered employers from using genetic information when making employment decisions, restricts them from requesting, requiring or purchasing genetic information, and strictly limits their disclosure of genetic information.

GENETIC INFORMATION

- Genetic information includes information about an individual's genetic tests and the genetic tests of an individual's family members.
- It also includes information about the manifestation of a disease or disorder in an individual's family members (that is, his or her family medical history).

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COVERED EMPLOYERS

Who must comply with Title II of GINA?

Title II of GINA applies to, among other entities, private employers with 15 or more employees, employment agencies, labor unions and joint labor-management training programs. Laws in several states also prohibit employment discrimination on the basis of genetic information, but those are not discussed here. Some of these laws may apply to employers with fewer than 15 employees.

DEFINITIONS

What is "genetic information"?

"Genetic information" includes:

- Information about an individual's genetic tests;
- Information about the genetic tests of a family member;
- 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 about an embryo legally held by the individual or family member using assisted reproductive technology.

What are examples of tests that would and would not be considered genetic tests?

Tests used to determine whether an individual has a certain genetic variant associated with an increased risk of acquiring a disease in the future are genetic tests. For example, a test to determine whether an individual has the genetic variants associated with a predisposition to certain types of breast cancer is a genetic test. Other examples of genetic tests include a test for a genetic variant for Huntington's disease and carrier screenings of adults using genetic analysis to determine the risk of conditions such as cystic fibrosis, sickle cell anemia, spinal muscular atrophy or fragile X syndrome in future offspring.

Examples of tests that are not genetic tests include an HIV test, a cholesterol test and a test for the presence of drugs or alcohol.

Does GINA protect individuals from discrimination on the basis of impairments that have a genetic basis, such as certain forms of breast cancer?

No. GINA is concerned primarily with protecting those individuals who may be discriminated against because an employer thinks they are at increased risk of acquiring a condition **in the future**. Someone who is discriminated against because he or she actually has breast cancer or another condition would not be protected by GINA, even if the condition has a genetic basis. The Americans with Disabilities Act (ADA), however, may protect such an individual whose cancer or other condition meets the definition of "disability."

PROHIBITION ON USE OF GENETIC INFORMATION IN MAKING EMPLOYMENT DECISIONS

Are there any situations in which an employer may use genetic information to make employment decisions?

No. An employer may never use genetic information when making employment decisions, since the possibility that someone may develop a disease or disorder in the future has nothing to do with his or her current ability to perform a job.

Does Title II of GINA prohibit harassment and retaliation?

Yes. GINA includes language similar to that used in Title VII of the Civil Rights Act of 1964 and other equal employment opportunity statutes prohibiting a wide range of discrimination, including harassment. GINA also includes a specific provision prohibiting employers from retaliating against employees who oppose employment practices made unlawful by GINA (for example, by refusing to provide genetic information) or who participate in an investigation, proceeding or hearing under GINA (for example, by filing a charge or by assisting others in filing a charge with the EEOC).

May an employer use genetic information about an applicant or employee to make decisions concerning health benefits?

No. Health benefits are part of the compensation, terms, conditions and privileges of employment. For example, an employer that fires an employee because of anticipated high health claims based on genetic information would violate Title II of GINA.

RESTRICTIONS ON ACQUISITION OF GENETIC INFORMATION

Title II of GINA generally prohibits employers from requesting, requiring or purchasing an applicant's or employee's genetic information, even if it is never used. In addition to asking an applicant or employee directly about genetic information, the EEOC's final rule says that a "request" for genetic information may include actions such as:

- 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.

May an employer ask for family medical history as part of a medical examination of a job applicant or employee?

No. Although an employer may conduct medical examinations after making a job offer or during employment as permitted by the ADA, the examination may not include collection of family medical

history. An employer must tell its health care providers not to collect genetic information as part of an employment-related medical exam and, if it finds out that family medical histories are being collected, the employer must take measures within its control (including not using the services of that health care provider) to prevent this from happening in the future.

Are there any situations in which a business may obtain genetic information without violating GINA?

Yes, there are six narrow exceptions to the rule that an employer may not request, require or purchase genetic information about an applicant or employee:

- Where the information is acquired inadvertently;
- As part of health or genetic services, including wellness programs, provided on a voluntary basis;
- In the form of family medical history, to comply with the certification requirements of the Family and Medical Leave Act (FMLA), state or local leave laws or certain employer leave policies;
- When the information comes from sources that are commercially and publicly available, such as newspapers, books, magazines and even electronic sources;
- As part of genetic monitoring that is either required by law or provided on a voluntary basis; and
- By employers who conduct DNA testing for law enforcement purposes as a forensic lab or for human remains identification.

When is the acquisition of genetic information considered inadvertent?

The EEOC's final rule discusses several situations in which the acquisition of genetic information may be inadvertent. For example, it would not violate GINA for a supervisor to overhear one employee tell another that her mother has breast cancer, or that the employee herself has had a test to determine whether she has the gene associated with increased risk for breast cancer. Similarly, this exception will apply when a supervisor receives genetic information in response to:

- A question about an employee's general well-being (for example, "How are you?" or "Did they catch it early?" asked of an employee who was just diagnosed with cancer); or
- A question about the general health of a family member (for example, "How's your son feeling today?" or "Did they catch it early?" asked of an employee whose family member was just diagnosed with cancer, or "Will your daughter be OK?").

Another example of inadvertent acquisition is when a supervisor receives an unsolicited communication about an employee's family member (for example, an email indicating that an employee's mother has cancer). An employer that lawfully requests documentation about an employee's current medical condition may also inadvertently receive genetic information, particularly family medical history.

What does GINA say about the acquisition of genetic information when an employer offers health or genetic services, like a wellness program?

GINA and the final rule say that an employer may acquire genetic information about an employee or his or her family members when it offers health or genetic services, including wellness programs, on a voluntary basis. The individual receiving the services must give prior, voluntary, knowing and written authorization.

While individualized genetic information may be provided to the individual receiving the services and to his or her health or genetic service providers, genetic information may only be provided to the employer in aggregate form. However, if information provided in the aggregate makes identification of specific individuals' genetic information possible because of the small number of participants in a wellness program, the employer will not violate GINA.

In addition, the final rule says that, while employers may offer certain kinds of financial inducements to encourage participation in health or genetic services under certain circumstances, they may not offer an inducement for individuals to provide genetic information. Thus, it would not violate Title II of GINA for an employer to offer individuals an inducement for completing a health risk assessment that includes some questions about family medical history or other genetic information, as long as the employer 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 to receive the inducement.

Title II allows employers to offer financial inducements for participation in disease management programs or other programs that encourage healthy lifestyles, such as programs that provide coaching to employees attempting to meet particular health goals (for example, achieving a certain weight, cholesterol level or blood pressure). To avoid a violation of Title II of GINA, however, employers who offer such programs and inducements to individuals based on their voluntarily provided genetic information must also offer the programs and inducements to individuals with current health conditions, and/or to individuals whose lifestyle choices put them at risk of acquiring a condition.

On May 17, 2016, the EEOC issued a final rule that clarifies that an employer may offer a limited incentive to an employee whose spouse provides information about his or her current or past health status as part of the employer's wellness program. This final rule provides that the value of the maximum incentive attributable to a spouse's participation may not exceed **30 percent** of the total cost of self-only coverage.

UPDATE: On Aug. 22, 2017, a federal district court ruled against the EEOC in a lawsuit challenging its final wellness program rule. According to the court, the EEOC failed to provide a reasoned explanation for adopting the final rule's 30-percent incentive limit. Rather than vacating the final rule, the court sent the rule back to the EEOC for reconsideration. It is not clear how the EEOC will respond to the court's ruling. Due to this new legal uncertainty and the possibility for employee lawsuits, employers should carefully consider the level of incentives they use with their wellness programs.

Why do GINA and the final rule include an exception that allows an employer to acquire family medical history as part of the FMLA's certification process, under certain state or local laws that allow employees to take leave to care for a family member or under certain employer leave policies?

Proving that an employee is entitled to leave to care for a family member with a medical condition under the FMLA, similar state or local laws or employer policies may require an employee to provide family medical history (that is, information about the manifestation of a disease or disorder in the family member) to the employer. Without the exception, requiring family medical history under these circumstances would violate GINA.

When would the exception permitting acquisition of genetic information from sources that are publicly and commercially available apply?

An employer is not liable under GINA for acquiring genetic information from sources that are commercially and publicly available, such as newspapers, books, magazines, periodicals, television shows, movies or the internet. For example, an employer would not be liable if it accidentally came across a newspaper article saying that an employee's father died of a sudden heart attack.

However, this exception does not apply to:

- Medical databases, court records or research databases available to scientists on a restricted basis;
- Sources with limited access, such as pages on social networking sites that require the creator's permission to access and to which access is not routinely granted;
- Commercially and publicly available sources that the employer accessed with the intent to obtain genetic information; or
- Sources from which a covered entity that accesses them is likely to acquire genetic information, whether or not they are commercially and publicly available.

May an employer conduct genetic monitoring to see if employees are being affected by harmful substances in the workplace?

Yes, if certain requirements are met. An employer that wants to do genetic monitoring that is not required by law must provide written notice of the monitoring program and must obtain an individual's prior, knowing, written and voluntary authorization. If the monitoring is required by law, such as under standards issued by the Occupational Safety and Health Administration (OSHA), an employer must provide notice of the monitoring and otherwise comply with the requirements for conducting the monitoring program, but it need not obtain the individual's prior, knowing, written and voluntary consent.

Furthermore, while individualized genetic information may be disclosed to the employee, and to the doctors and certified genetic counselors involved in the monitoring, the employer may only be given

genetic information in aggregate form. As in the case of health or genetic services offered by an employer on a voluntary basis, if information provided in the aggregate makes identification of specific individuals' genetic information possible because of the small number of participants in a monitoring program, the employer will not violate GINA.

The final rule clarifies that GINA prohibits an employer from retaliating or otherwise discriminating against an employee who refuses to participate in genetic monitoring that is not specifically required by law. An individual who refuses to participate in a voluntary genetic monitoring program should be informed of the potential dangers (that is, the consequences that might result if the effects of certain toxins in the workplace are not identified), but the employer may not take any adverse action against the individual for refusing to participate. However, an employer does not violate Title II of GINA if it limits or restricts an employee's job duties based on genetic information because it was required to do so by law or regulation, such as regulations administered by OSHA.

What does GINA say about whether an employer may acquire genetic information for law enforcement purposes or for human remains identification?

GINA permits employers that engage in DNA testing for law enforcement purposes as a forensic laboratory, or for purposes of human remains identification, to collect their employees' genetic information in certain limited circumstances. Specifically, these entities may request or require genetic information only to the extent that the information is used for analysis of DNA identification markers for quality control to detect sample contamination.

REQUESTING HEALTH-RELATED INFORMATION

What should an employer do to comply with GINA when lawfully requesting health-related information from an employee?

Although the proposed rule said that the acquisition of genetic information as the result of an inquiry about an individual's current health status would be considered inadvertent if the request was lawful, the final rule says that, when an employer makes a request for health-related information (for example, to support an employee's request for reasonable accommodation under the ADA 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 warning may be written or oral (if the employer typically does not make such requests in writing).

The final rule suggests language such as the following:

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.

If this type of warning is provided, any resulting acquisition of genetic information will be considered inadvertent, and therefore not in violation of GINA. In other words, use of this type of warning creates a "safe harbor" for employers who receive genetic information in response to a request for health-related information.

Must the warning be provided every time an employer requests health-related information from an employee?

To take advantage of this safe harbor, the employer must do what is reasonably necessary to ensure that the warning is understood by employees or doctors submitting health-related information to the employer, at the time of submission. This is best accomplished by providing the warning each time health-related information is requested. But it may suffice to give the warning more generally (for example, by including it on the employer's leave and reasonable accommodations request forms), if doing so would reasonably ensure that it is understood at the time health-related information is submitted.

What if an employer does not provide a warning like the one the EEOC suggests when it requests health-related information and receives genetic information in response?

If the employer's request for health-related information was made in a way that was likely to result in the employer obtaining genetic information, the request violates GINA.

On the other hand, if the employer's request was not made in a way that was likely to result in the acquisition of genetic information, any genetic information it acquires would be considered an inadvertent acquisition. For example, an employer who asks an employee to provide a doctor's note explaining a five-day absence will not violate GINA if the doctor includes the family medical history taken as part of the employee's medical examination, even if the employer has not warned the employee or the doctor against providing genetic information.

CONFIDENTIALITY

What are GINA's rules on confidentiality?

An employer in possession of genetic information about applicants or employees must treat it the same way it treats medical information generally. It must keep the information confidential, and, if the information is in writing, must keep it apart from other personnel information in separate medical files. **Genetic information may be kept in the same file as medical information subject to the ADA**.

There are limited circumstances under which an employer may disclose genetic information:

- To the employee or family member about whom the information pertains, upon receipt of the employee's or family member's written request;

- To an occupational or other health researcher conducting research in compliance with 45 CFR Part 46;
- In response to a court order, except that the employer may disclose only the genetic information expressly authorized by the order;
- To government officials investigating compliance with Title II of GINA, if the information is relevant to the investigation;
- In accordance with the certification process for FMLA leave or state family and medical leave laws; or
- To a public health agency, but only with regard to information about the manifestation of a disease or disorder that concerns a contagious disease that presents an imminent hazard of death or life-threatening illness.

Genetic information placed in personnel files prior to GINA's effective date on Nov. 21, 2009, need not be removed, and an employer will not be liable under GINA for the mere existence of that genetic information in a personnel file. However, disclosing that genetic information to a third party is prohibited.

RELATIONSHIP TO OTHER LAWS

What effect does Title II of GINA have on other laws addressing genetic discrimination in employment?

State or local laws that provide equal or greater protections from employment discrimination on the basis of genetic information still apply. Additionally, Title II of GINA does not limit the rights or protections under federal, state, local or tribal laws that provide greater privacy protection to genetic information, and does not affect an individual's rights under the ADA, the Rehabilitation Act or state or local disability discrimination laws.

CHARGES OF DISCRIMINATION

What happens when an employee files a charge under GINA?

Someone who believes that his or her employment rights have been violated on the basis of genetic information may file a "charge of discrimination" with the EEOC within 180 days from the date of the alleged violation (or within 300 days if a state or local agency enforces a law that prohibits employment discrimination on the basis of use or acquisition of genetic information or genetic testing).

If a charge is filed, the EEOC will notify the employer and provide an investigator's name and contact information. The parties may choose to resolve the dispute through settlement, or, in some cases, mediation. If the dispute is not resolved voluntarily, the investigator will ask both parties for information. The employer may be asked to:

- Provide a position statement;

- Provide copies of policies, files or other evidence;
- Allow on-site visits; and
- Make employees available for interview.

Once the investigation is complete, the EEOC will determine whether there is "reasonable cause" to believe discrimination occurred. If there is insufficient evidence to find reasonable cause, the EEOC will issue a Dismissal and Notice of Rights stating that the charging party has a right to file a lawsuit in federal court within 90 days of receipt of the notice.

If reasonable cause is found, the EEOC will issue a Letter of Determination and try to conciliate the charge. Where the charge cannot be resolved through conciliation, the EEOC will either file a court action or issue a Notice of Right to Sue stating that the charging party has a right to file a lawsuit in federal court within 90 days of receipt of the notice. A charging party may also request a Notice of Right to Sue from the EEOC 180 days after the charge was first filed with the EEOC. For a detailed description of the process, please refer to the EEOC website.

What are the remedies for a violation of GINA Title II?

The same remedies available under Title VII of the Civil Rights Act of 1964 are available under Title II of GINA. An aggrieved individual may seek reinstatement, hiring, promotion, back pay, injunctive relief, monetary damages (including compensatory and punitive damages) and attorneys' fees and costs. Title VII's cap on combined compensatory and punitive damages also applies to actions under Title II of GINA. The cap on combined compensatory and punitive damages (excluding past monetary losses) ranges from $50,000 for employers with 15-100 employees to $300,000 for employers with more than 500 employees.

Source: U.S. Equal Employment Opportunity Commission