The New Genetic Information Nondiscrimination Act: Basics and Compliance Tips

Employers should get ready now for the effective date of a new federal statute barring discrimination based on genetic information in employment and for health insurance purposes

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On May 21, 2008, after more than a decade of considering various forms of the bill, Congress passed, and President Bush signed, the Genetic Information Nondiscrimination Act (GINA), Pub. L. No. 110-233, 122 Stat. 881 (2008). GINA prohibits discrimination based on genetic information both in employment and health insurance. The employment-related provisions take effect on Nov. 21, 2009. Although for most employers GINA breaks no new ground, all employers should take note of its provisions and their interaction with a wide variety of other federal and state laws.

GINA Basics

GINA protects applicants and employees already protected under Title VII of the Civil Rights Act of 1964. Employers subject to the law include those subject to Title VII (those employing at least 15 employees), entities employing state employees and most federal employers.

GINA defines "genetic information" as information about:

1) an individual's genetic tests;
2) genetic tests of an individual's family members; and
3) the manifestation of a disease or disorder in an individual's family members.

"Genetic information" does not mean information about the sex or age of any individual.

"Family member" means: (1) a dependent; or (2) a first, second, third or fourth-degree relative (which includes all blood relatives out to the level of great-great-grandparents, great aunts and uncles and first cousins).

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GINA makes it an unlawful employment practice for an employer, employment agency or labor union:

1) to fail or refuse to hire, or to discharge any employee, or to otherwise discriminate against any employee, regarding the compensation, terms, conditions or privileges of employment, due to genetic information; or

2) to limit, segregate or classify employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect employee status because of genetic information.

In other words, employers cannot use genetic information in making decisions about its employees that should be based on qualifications, adding genetic information to the list of protected categories enumerated in Title VII and numerous state laws prohibiting discrimination based on factors such as gender, race, disability, etc.

GINA also makes it illegal for an employer to request, require or purchase genetic information for an employee or a family member, with certain exceptions. Those exceptions include most of the everyday instances in which such information might come to an employer's attention, including when such information is requested as part of the certification process for leave under the Family and Medical Leave Act (FMLA) or state family and medical leave laws.

Exceptions to the prohibition against requesting or requiring disclosure of genetic information also include situations in which an employer uses the information to monitor the effects of toxic substances in the workplace and the employer provides written notice of the monitoring to the employee and informs him or her of the results. The employer must also gain prior, written, knowing and voluntary authorization from the employee unless the testing is required by state or federal law. Any such monitoring must be performed in compliance with federal or state regulations, and the employer must receive the results of the monitoring only in an aggregate form that does not tie specific data to individually identified employees.

GINA further requires that if an employer, employment agency, labor organization or joint labor management committee possesses genetic information, that information must be maintained in a separate confidential file and not in the employee's personnel file.

Executive Order 13145

GINA mirrors in many ways Executive Order 13145, which prohibits genetic discrimination in the executive branch of government. The Equal Employment Opportunity Commission (EEOC) provides examples in Executive Order 13145 that, by analogy, could apply to GINA. (*See* EEOC Policy Guidance on Executive Order 13145: To Prohibit Discrimination in Federal Employment Based on Genetic Information (2000), available at http://www.eeoc.gov/policy/docs/guidance-genetic.html.)

> **Example 1.** Vanessa finds out that Peter's mother recently passed away because of leukemia and that her sister is seriously ill with the same disease. Peter is an excellent performer in Vanessa's research division. Budget cuts in the division will require layoffs, and Vanessa will lose two employees. If she identifies Peter's position for elimination because of his family history of leukemia, she will be violating the executive order and GINA.
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> **Example 2.** Lisa works in a federal agency, and she participates in a breast cancer study that includes genetic testing. Her supervisor finds out about Lisa's participation and

denies her request for a detail to another position that would enhance her career. Lisa had expressed interest in this detail and is very qualified for it. The only reason her supervisor refused her request is because of her participation in the breast cancer study. Her supervisor violated the executive order and probably GINA.

Example 3. An agency makes a conditional offer to Mark, Luke and Martin to work as firefighters. All three are required to take a medical examination, which includes an inquiry into family medical histories. Mark discloses a history of heart disease in his family. Essential functions of a firefighter's job include putting out fires and performing certain emergency procedures, but physical limitations from heart disease could prevent Mark from performing these functions. Based on his family's medical history, the government could conduct more medical assessments to determine whether Mark is currently suffering from the kind of heart disease that could prevent him from performing the essential functions of the job. This is not a violation of the executive order and probably not a violation of GINA.

Compliance Implications

GINA has implications for compliance with the Americans With Disabilities Act (ADA) and similar state laws, the FMLA and similar state leave laws, and the Health Insurance Portability and Accountability Act (HIPAA).

Direct Discrimination

Employers may not make employment-related decisions based on genetic information, no matter how well-intentioned. For example, if an employee is known to have had cancer, or to have a family history of it, the employer cannot consider that factor in deciding whether to place that employee into a position that involves exposure to agents known to increase the likelihood of cancer.

Compliance Tip: Amend your Equal Employment Opportunity policies to add genetic information as one of the protected categories upon which employment decisions will not be based.

Americans With Disabilities Act

Most violations of prohibitions against discrimination based on genetic information involve pre-employment and accommodation related to physical examinations. These physicals are allowed under the ADA during the course of employment when they are job-related and consistent with business necessity. ADA violations occur when the physicals are not reasonably related to the job, when they are inconsistent with business necessity or when the employer seeks information that exceeds the very limited scope it is entitled to. The EEOC provides several examples that explain these principles. (*See* EEOC Enforcement Guidance: Disability-Related Inquiries and Medical Examinations of Employees Under the American With Disabilities Act (ADA) (2000), available at http://www.eeoc.gov/policy/docs/guidance-inquiries.html.)

Example 1. A supervisor heard that a secretary is afraid that she may have breast cancer because she had a lump in her breast. Since then, the secretary's performance has not changed; she still comes to work and performs her duties well and efficiently. The employer thus cannot have a reasonable belief that the secretary cannot perform her essential job functions or that she will pose a direct threat to someone because of her possible medical condition. The employer cannot make any inquiries related to the secretary's purported disability, let alone her genetic information.

> **Example 2.** Adam is a tax auditor for a federal agency. Although normally an excellent performer, Adam has been completing one-third fewer audits than the average competent employee. He has also made several mistakes in his audits, such as assessing whether taxpayers had provided the correct documentation for their claimed deductions. His supervisor asks him about his poor performance, and Adam explains that his lupus medication makes him lethargic and unable to concentrate. Based on the objective facts of Adam's poor performance and his explanation, the employer has a reasonable belief that Adam is unable to perform the essential functions of his job because of his lupus. The employer may thus make disability-related inquiries, including asking for documentation from Adam's physician explaining how the medication affects Adam's ability to perform his job.

Even in Adam's situation, however, employers do not have carte blanche to inquire into or access all of an employee's medical information. An employer is entitled only to the information necessary to determine whether an employee: (1) will be able to perform the essential functions of his or her job; or (2) poses a direct threat. Documentation is sufficient for this when it describes the nature, severity and duration of the employee's disability; the activity or activities that the disability limits; and the extent to which the disability limits the employee's ability to perform the activity or activities. Documentation can substantiate why the requested reasonable accommodation is needed. This means that in most circumstances, an employer cannot ask for an employee's complete medical file because that information will be beyond what is necessary for the employer's purposes.

The limitation on the scope of inquiries, even when there is a reason to make an inquiry, means that it will be rare for genetic information to necessarily be disclosed. For example, Adam's family may have a history of lupus, but that is not necessary to describe his own disability and how it will limit his performance. Inquiries about this genetic information would violate the ADA and could expose an employer to liability under GINA.

Even if job-related and consistent with business necessity, employers may not have their doctors conduct genetic testing as part of such examinations without the employee's written authorization and without treating the results as outlined in GINA. A key concept here is that "genetic information" as the statute defines it includes family history that is customarily taken at the beginning of a physical examination.

Compliance Tip – Scope of Examination: Make sure that all examinations are job related and consistent with business necessity, and that the doctor only reveals such information as is necessary for you to make decisions based on factors that are job related and consistent with business necessity. Any communications with doctors, such as examination request forms, should specifically state that the examiner is not to go beyond this scope in the examination and is not to reveal protected information to you unless necessary within this scope.

Compliance Tip – Consent: Analyze each step of a medical examination separately to determine whether you have informed consent for each step. Employees should sign consent forms that explicitly describe the testing to take place.

FMLA and Other Leaves

While GINA allows employers to obtain genetic information when necessary to certify a need for leave under the FMLA or similar state laws, it does not extend the exception to other kinds of leave – such as the use of regular sick leave or personal time off to care for an ill family member.

Compliance Tip: Examine your leave request forms to ensure that they do not request disclosure of information beyond that which you are entitled.

ADA/FMLA Recordkeeping

It is important to note that GINA requires that genetic information be kept in a separate file. While earlier versions of the bill required that it be maintained separate even from other medical information (which all employers should keep separate from the employee's personnel file and available only for review in connection with medical related issues), GINA allows the genetic information to be maintained in the separate medical file. However, GINA allows disclosure of genetic information in more limited circumstances than would normally apply to medical information.

Compliance Tip: Maintain any genetic information in a separate file containing only medical information and flag any documents that contain genetic information so that they can be redacted before producing the medical file for any purpose for which examination of the genetic information is not appropriate. If your employee handbook includes any discussion of personnel files, be sure to mention that medical information is maintained in a separate confidential file.

HIPAA Compliance

HIPAA already provides that protected health information (PHI) includes genetic information. GINA also prohibits insurers from using genetic information to make coverage and premium determinations.

Compliance Tip – Communication to Employees: Any statements that employers distribute to employees regarding PHI should be amended to clarify that genetic information is considered PHI.

Compliance Tip – Employers should consider requesting written assurance from their health care insurance providers that they do not include genetic information in their determination of insurance premiums.

For More Information

This article is one of 25 chapters on the most recent HR developments published in *Human Resources 2009: Answers to Your 25 Top Questions, Winter Edition*.