

in this issue:

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On May 21, 2008, President Bush signed into law the Genetic Information Non-Discrimination Act (GINA) prohibiting employment discrimination based on employees' genetic information. The Act also restricts employers' collection, use, and disclosure of employees' genetic information.

Genetic Antidiscrimination Law Creates New Compliance Challenges for Employers

By Philip L. Gordon and Jennifer L. Mora

Nearly seven years after declaring in a Presidential Radio Address that “[g]enetic discrimination is unfair to workers and their families” and that “[t]o deny employment or insurance to a healthy person based only on a predisposition violates our country’s belief in equal treatment and individual merit,” on May 21, 2008, President George W. Bush signed the Genetic Information Nondiscrimination Act of 2008 (GINA). Intended to encourage Americans to take advantage of advances in the genetic sciences without fear of adverse consequences, GINA provides broad protections in employment and health benefits against the improper collection, use or disclosure of employees’ genetic information. Although GINA does not become effective until November 21, 2009, employers should immediately begin taking steps to ensure compliance with the Act.

Background

For nearly a decade, Congress has attempted to pass federal protections against genetic discrimination, especially in the context of health insurance and employment. Although Congress ultimately passed GINA overwhelmingly, there has been a heated debate over the need for federal legislation. Opponents noted that more than 40 states prohibit genetic discrimination in health insurance, and more than 30 states prohibit genetic discrimination in the workplace. Moreover, in 2000, then-President Bill Clinton signed an Executive Order that prohibits the federal government from requiring its employees to submit to any

type of genetic test and from using an applicant’s or employee’s genetic information to make employment decisions.

Opponents also argued that existing federal statutes already prohibit the type of discrimination and use of information that GINA now expressly governs. For example, the Americans with Disabilities Act (ADA) comprehensively regulates an employer’s right to collect, use, and disclose medical information during the hiring and accommodations process and protects disabled employees against employment discrimination. In addition, regulations promulgated under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) restrict an employer’s ability to collect, use, and disclose genetic information when acquired through the administration of an employer-sponsored group health plan.

Congress, nonetheless, determined that GINA’s passage was necessary to “establish[] a national and uniform basic standard ... to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.”

Gina’s Impact on Employers

GINA’s Antidiscrimination Provisions

GINA expands Title VII of the Civil Rights Act of 1964 by imposing broad restrictions on the collection, use and

disclosure of genetic information in the employment context. GINA applies to all employers who are subject to Title VII (i.e., those with 15 or more employees), as well as to employment agencies and labor organizations as those terms are defined in Title VII.

The starting point to understanding GINA's impact on employers is the Act's definition of *genetic information*. That definition encompasses not only the genetic tests of employees and their family members but also any "manifestation of a disease or disorder" in the employee's family members. The latter portion of the definition is intended to prevent an employer from inferring that an employee is predisposed to the same disease or disorder as a family member. Significantly, the Act defines *family member* expansively to include not only the employee's dependents but also relatives of the employee, or of the employee's dependents, from the first to the fourth degree. In other words, information about the manifested diseases or disorders of an employee's mother, grandmother, great grandmother, and great great grandmother would constitute "genetic information," for purposes of the Act.

GINA imposes three principal restrictions on employers with respect to genetic information. First, employers cannot discriminate in the terms or conditions of employment based upon genetic information. Second, employers are prohibited from retaliating against an employee who opposes genetic discrimination. Third, employers generally are barred from collecting genetic information about an employee, or an employee's family member, whether by request, mandatory disclosure, or purchase from a third party.

The restriction on collecting genetic information has several important exceptions. Most significantly, GINA allows employers to request or require the disclosure of a family member's genetic information, including manifested diseases or disorders, to comply with the Family and Medical Leave Act (FMLA) and state family and medical leave laws. In narrowly defined circumstances, employers

may request or require the disclosure of genetic information to monitor the biological effects of toxic substances in the workplace. Employers do not violate GINA if they purchase commercially and publicly available documents, such as periodicals (but excluding medical databases and court records), which contain genetic information about an employee or an employee's family member. Employers also do not violate GINA by "inadvertently" requesting or requiring family medical history, highlighting the need for employers to eliminate intentional requests for family medical histories.

Recognizing that employers may now, or in the future, offer "genetic services" as an employee benefit — for example, genetic counseling as part of a wellness program, GINA carves out an exception for requests for genetic information in connection with such services. To qualify, the employee must provide prior, voluntary, and written authorization for disclosure of genetic information to the service provider; only the employee and the licensed health care professional or board certified genetic counselor involved in providing the services may receive individually identifiable information related to the service; and no individually identifiable information related to the service may be disclosed to the employer. These provisions mean that, as a practical matter, an employer's involvement in an offering of genetic services should be limited to structuring and paying for the service.

With respect to enforcement, GINA incorporates Title VII's remedial scheme. Employees must exhaust administrative remedies before initiating a lawsuit, and damage awards are subject to the same restrictions as those applicable to Title VII. Also like Title VII, GINA does not preempt more stringent state laws. Unlike Title VII, GINA does not at this time permit claims based on a disparate impact theory. However, the EEOC is authorized to create a commission to review the developing science of genetics and to make recommendations as to whether disparate impact claims should be permitted.

GINA's Confidentiality Provisions

Employers are required to apply the same confidentiality protections for "genetic information" as are applicable to other types of medical information protected under the ADA. In other words, genetic information must be treated as confidential, maintained on separate forms and in separate medical files, and internal access must be strictly limited to those with a need to know.

Although GINA generally prohibits employers from disclosing genetic information to third parties, the statute provides a few exceptions. GINA allows disclosures (a) necessary for the employee to comply with federal or state medical leave laws, (b) to government agencies investigating compliance with GINA, and (c) in response to a court order provided that the employer notifies the employee of the disclosure if the court order was issued without the employee's knowledge. Employers also may disclose to federal, state, or local public health agencies that an employee's family member has manifested a contagious disease if the disease presents an imminent hazard of death or life-threatening illness and the employee is notified of the disclosure.

GINA's Application to Group Health Plans

GINA also amends ERISA to restrict the collection and use of genetic information in connection with group health benefits. Most fundamentally, the Act bars group health plans and health insurance issuers from adjusting contribution amounts or premiums for the group based on the genetic information of any plan participant, albeit premiums can be increased based upon the manifestation of a disease in a plan participant. GINA also generally prohibits plans from requesting or requiring individuals or their family members to undergo a genetic test and from requesting, requiring or purchasing genetic information for underwriting purposes or prior to an individual's enrollment. A plan or insurance issuer can use genetic test results for payment purposes. Finally, genetic information now expressly falls within HIPAA's definition of "protected

health information” and must be treated as such when in the plan’s or issuer’s possession.

The Act authorizes the Labor Department to impose penalties of \$100 per day of violation per affected individual, with a minimum penalty of \$15,000 for material violations and of \$2,500 for de minimis violations.

Practical Implications for Employers

GINA’s practical implications are likely to be broad if GINA achieves the intended objective of encouraging more individuals to take genetic tests and to seek out genetic counseling. While these implications are difficult to foresee, the Act itself suggests the following actions that employers should consider taking by the effective date:

- Add non-discrimination on the basis of genetic information to equal employment opportunity statements;
- Discontinue requests to applicants and employees to provide a family medical history;
- Avoid requesting information about the manifested disorders or diseases of an employee’s family members for leave requests unrelated to the FMLA or state analogues;
- Evaluate whether any changes are necessary in connection with the administration of health benefits;
- Screen all employee medical information upon receipt to determine whether that information might fall within the broad definition of “genetic information” and, if so, provide required confidentiality protections; and
- Implement policies and procedures to prevent the inadvertent disclosure of genetic information in response to a subpoena or civil discovery request unaccompanied by a court order compelling disclosure.

To date, only a very small number of cases alleging genetic discrimination have been reported. GINA’s enactment should not result in a new flood of litigation if employers promptly address their compliance obligations under the Act.

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