



1501 M Street NW, 7th Floor
Washington, DC 20005
tel 202.466.6550 | fax 202.785.1756

MEMORANDUM

To: Health Care Clients and Friends
From: Powers, Pyles, Sutter & Verville, PC
Date: November 20, 2009
Re: Genetic Information Nondiscrimination Act of 2008

This memorandum provides an overview of the Genetic Information Nondiscrimination Act of 2008 (“GINA”) a portion of which will go into effect on November 21, 2009. GINA prohibits discriminatory practices based on an individual’s genetic information or family medical history. Title I prohibits health insurers from using genetic information for enrollment and underwriting purposes while Title II prohibits the use of an individual’s genetic information in making employment decisions. This memorandum focuses primarily on Title II, highlighting the issues and practices employers will have to alter in order to comply with GINA.

I. Title I

Title I amends portions of the Employee Retirement Income Security Act of 1974 (“ERISA”), the Public Health Service Act and the Internal Revenue Code to regulate group health plans’ and insurers’ use of genetic information for underwriting and enrollment purposes. This Title went into effect on May 21, 2009. Interim final regulations were issued on October 7, 2009.¹ Title I does not require insurers to provide specific benefits related to health services or genetic testing but prohibits insurers and group health plans from using an individual’s genetic information to raise premiums for the group or individual. Additionally, insurers and group health plans may not request or require an individual or family member to undergo a genetic test or submit genetic information, including family medical history, prior to, or in conjunction with enrollment for the purposes of underwriting.

¹ 74 Fed. Reg. 51664 (Oct. 7, 2009).

II. Title II

Title II applies to private employers who have 15 or more employees as well as state, local and federal governments, employment agencies, labor unions and joint labor-management training programs which are referred to as “covered entities” under Title II of GINA.² The Equal Employment Opportunity Commission (EEOC) issued a notice of proposed rulemaking (NPRM) on March 2, 2009.³ While final regulations have not been issued, Title II goes into effect on November 21, 2009.

Title II prohibits covered entities from discriminating against employees on the basis of the individual’s or family member’s genetic information or medical history. Also, employers may not request, require or purchase such information. Genetic information is defined as information from genetic tests, genetic tests of family members and family medical history.⁴ A family member encompasses dependents, who are related or become related through marriage, birth, adoption or placement for adoption and those related from the first through fourth degrees.⁵ GINA defines a genetic test as “an analysis of human DNA, RNA, chromosomes, proteins or metabolites that detects genotypes, mutations or chromosomal changes.”⁶ For a disease with a genetic component, a test will not be considered a “genetic test” if there is clear manifestation of the disease itself, meaning that “an individual has been or could reasonably be diagnosed with the disease, disorder or pathological condition by a health care professional with appropriate training and expertise in the field of medicine involved.”⁷

Under GINA, employers cannot engage in discriminatory practices such as refusing to hire or discharging an employee or imposing any segregation, classification or limitations on employees that “would deprive or tend to deprive employees of employment opportunities or adversely affect the status of an employee as an employee” due to genetic information or family medical history.⁸ The covered entity may not discriminate against an employee in terms of compensation, privileges or conditions.⁹ Genetic discrimination also encompasses employment decisions or discrimination based on knowledge that an employee or member received a genetic service or test, irrespective of the actual results of the test.¹⁰

As noted above, an employer may not request, require or purchase genetic information of an employee unless it meets one of the statutorily delineated exceptions. These exceptions include situations where an employer inadvertently requests or requires family medical history or genetic information as part of a request for accommodation under the Americans with Disabilities Act (ADA) or under a family and medical leave request or overhears such information unintentionally. These incidences will be considered inadvertent so long as the

² 29 C.F.R. § 1635.2 (incorporating definitions of employees/employers from the Civil Rights Act of 1964, 42 U.S.C.2000e).

³ 74 Fed. Reg. 9056 (March 2, 2009).

⁴ 29 C.F.R. § 1635.3.

⁵ 74 Fed. Reg. at 9056, 9058-59 (March 2, 2009).

⁶ 29 C.F.R. § 1635.3.

⁷ *Id.*

⁸ *Id.*

⁹ 29 C.F.R. § 1635.4.

¹⁰ 74 Fed. Reg. at 9059.

request was lawful and the information limited to only the relevant information. Employers may request genetic information or offer genetic services as a component of wellness programs so long as the employee provides authorized, written consent and the individually identifiable information concerning the results of the test is provided to the employee and not disclosed to the employer. An employer may also acquire genetic information via public or commercial sources. Lastly, there are exceptions for the monitoring of biological effects of toxic substances and for certain law enforcement purposes. It is important note that while there are statutory exceptions to requesting or requiring genetic information, there are no exceptions to using genetic information in making employment decisions, regardless of how the information was acquired.¹¹

Confidentiality

Genetic information about an employee or member must be maintained as part of the confidential medical record. The genetic information may be kept in the same file as other medical information so long as it is separate from other personnel files.¹² This information may be disclosed in certain circumstances including but not limited to a court order, for public health purposes or for a family and medical leave request.¹³

GINA does not alter the privacy protections under the Health Insurance Portability and Accountability Act (HIPAA). Genetic information that is also protected health information under HIPAA is carved out from GINA; therefore there are no restrictions on the use or disclosure of genetic information so long as the disclosure adheres to HIPAA.¹⁴ For example, where a health care provider renders health or genetic services, the genetic information obtained is subject to the HIPAA privacy rule not GINA. In contrast, where a hospital obtains the genetic information of an employee, in its position as an employer, the hospital would be subject to GINA, in the use of and treatment of the employee's genetic information.¹⁵

Preemption

GINA does not preempt any other state or federal laws that provide equal or stronger protections against genetic discrimination in the workplace.¹⁶ GINA modifies the ADA by prohibiting employers from requesting medical history or genetic information as part of the physical conducted for post-applicants.¹⁷

Remedies

The remedies available include reinstatement, back pay, injunctive relief or compensatory damages. The law prohibits employers from retaliating against any individual who has made a charge, testified or is involved in a proceeding under this Act.

¹¹ Background Information for EEOC Notice of Proposed Rulemaking on Title II of the Genetic Information Nondiscrimination Act of 2008, www.eeoc.gov/policy/docs/qanda_geneticinfo.html.

¹² 42 U.S.C. 12112(d)(3)(B).

¹³ 29 C.F.R. § 1635.9.

¹⁴ 74 Fed Reg. at 9065.

¹⁵ *Id.*

¹⁶ 29 C.F.R. §1635.11.

¹⁷ 74 Fed Reg. at 9065.

III. Conclusion

Many employers are likely to encounter genetic information or family medical history whether through a wellness benefit program or a request for family and medical leave or as part of a pre-employment physical. Consequently, employers must ensure that genetic or medical information is not requested or falls within the enumerated exceptions to comply with GINA. It is important to note that the current health reform bills pending in Congress may alter or override components of GINA, thus employers should be prepared for additional changes in this area.