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Genetic Information Nondiscrimination Act Is Signed

The Genetic Information Nondiscrimination Act of 2008 has been signed into law. The new law provides broad protections for individuals with respect to the use of genetic information by health plans and employers. Employers should review their health plans and employment practices to confirm they are in compliance with the new law.

Background

Thirteen years after its first introduction, federal law prohibiting discrimination on the basis of genetic information has been enacted. The Genetic Information Nondiscrimination Act of 2008 (GINA) was signed by President Bush on May 21, 2008.

Overview of GINA

Title I of GINA amends the nondiscrimination rules under the Health Insurance Portability and Accountability Act (HIPAA) provisions of ERISA, the Public Health Service Act, and the Internal Revenue Code (IRC) to prohibit genetic discrimination by group health issuers and group health plans with respect to eligibility and premium contributions. It also amends the Social Security Act to require the Secretary of Health and Human Services (HHS) to revise the HIPAA privacy regulations to clarify how those rules apply to genetic information.

Title II prohibits employers from using genetic information as a basis for discriminating against an individual with respect to hiring, firing or other terms and conditions of employment.

The term "genetic information" for purposes of both Titles I and II includes information about an individual's or an individual's family member's –

- genetic tests
- request for, or receipt of, genetic services
- participation in clinical research which includes genetic services
- manifestation of a disease or disorder in an individual's family members.

Family members are broadly defined to include individuals who are dependents under HIPAA special enrollment rules (i.e., anyone eligible for enrollment under the plan as a dependent of an employee), any other first, second, third or fourth degree relative, and a fetus or embryo.

BUCK COMMENT. *Title I applies to both ERISA and non-ERISA plans (e.g., church plans, governmental plans) regardless of size. It generally does not apply to benefits that are otherwise excepted from HIPAA, such as accident or disability insurance or workers' compensation insurance. However, these types of benefits may fall under Title II as a term and condition of employment.*

Title I – Genetic Nondiscrimination in Group Health Plans

Under Title I, employer-sponsored group health plans and health insurers providing group health plan coverage are prohibited from restricting enrollment or adjusting premium or contribution amounts for the group on the basis of genetic information. They may not request, require or purchase genetic information prior to an individual's enrollment in the plan or request or require genetic testing of the individual or a family member for underwriting purposes. However, a plan or issuer that obtains such information incidental to the collection of other information prior to enrollment will not be in violation of the law as long as it is not used for underwriting purposes. Further, under certain circumstances, a plan may request an individual to voluntarily undergo a genetic test as part of a research study, as long as the results are not used for underwriting purposes.

BUCK COMMENT. *GINA allows a health insurer to increase overall premiums charged to a plan sponsor if an individual enrolled in the plan has manifested a disease or disorder with a genetic basis. However, the insurer cannot increase premium rates by assuming a higher risk for the group as a whole based on this genetic information.*

GINA makes clear that a group health plan or a group health issuer may obtain and use the results of genetic tests in making payment determinations, consistent with the definition of payment used in the HIPAA privacy regulations. The HIPAA privacy regulations define payment broadly and include a wide array of activities undertaken by a health plan such as obtaining premiums, determining eligibility, billing, claims management, collection activities, medical necessity reviews, and preauthorization of services.

BUCK COMMENT. *This is welcome news for health plans and insurers, indicating that business may continue as usual when processing claim payments – authorization from the individual is not required prior to obtaining or using genetic information for payment purposes.*

The new law also amends the Social Security Act to require the Secretary of HHS to revise the HIPAA privacy regulations to clarify that genetic information is treated as health information and to make them otherwise consistent with the restrictions placed on the use of genetic information under other provisions of GINA – e.g., prohibiting the use or disclosure of genetic information by a HIPAA covered entity for underwriting purposes and including definitions of the terms "genetic information," "genetic testing" and "family member" that are consistent with the definitions in GINA.

BUCK COMMENT. *Some employers may need to update their HIPAA privacy and security policies and issue new HIPAA notices to reflect the new nondisclosure of genetic information rules.*

Title II – Genetic Nondiscrimination in Employment

Title II prohibits employers from failing or refusing to hire, discharging, or otherwise discriminating against an employee with respect to the compensation, terms, conditions, or privileges of employment because of the genetic information of the employee or his or her family members. In addition, employers may not limit, segregate or classify employees because of genetic information in a way that would deprive them of employment opportunities or otherwise adversely affect their status as employees.

Employers generally may not request, require or purchase genetic information with respect to an employee or his or her family members. However, there are six specific exceptions –

- when the employer obtains genetic information inadvertently when requesting or requiring a family medical history
- when offering health or genetic services (including as part of a wellness program), the employer obtains proper consent and only receives de-identified aggregate information of all participating employees
- when the information is requested or required to comply with FMLA or similar state family and medical leave laws
- when the employer purchases commercially and publically available documents that include family medical history (e.g., newspapers, magazines, but not medical databases or court records)
- where the information is used for genetic monitoring of the biological effects of toxic substances in the workplace
- where the employer conducts DNA analysis for law enforcement purposes as a forensic laboratory.

***BUCK COMMENT**. Employers should exercise caution when engaging in any activity that collects an employee's family health history. Those who sponsor wellness programs and use health risk appraisals may need to review their procedures.*

Employers also need to understand the exceptions noted above are the only ones they can rely on to avoid potential violations of the law.

Confidentiality Requirements. Employers that possess genetic information must maintain it on separate forms in separate files and treat it as a confidential medical record, consistent with the standards under the Americans With Disabilities Act. Employers may not disclose any genetic information they have received except to the employee upon written request, to an occupational or other health researcher, in response to a court order, to a government official investigating a GINA complaint, for FMLA or state leave law purposes or to a public health agency.

Penalties

Title I imposes new ERISA penalties consistent with those under IRC Section 4980D (i.e., those imposed for violations of the HIPAA portability rules). A penalty of $100 per day for each individual to whom the failure applies may be imposed against the plan sponsor or issuer and there are maximum penalties depending on the time of discovery and whether use of reasonable diligence would have revealed the failure. As under Section 4980D, the DOL has discretion to limit or waive penalties altogether.

Section 4980D is also amended to subject violations of Title I to penalties under that section.

Title II is enforced under Title VII of the Civil Rights Act of 1964. Under Title VII, a court may enjoin the employer from engaging in the violating practice and order affirmative action including reinstatement or hiring of employees (with or without back pay) or other equitable relief. In cases where intentional discrimination exists, the employee may also recover compensatory and punitive damages from the employer (other than a government, government agency or political subdivision) if it is demonstrated that the employer acted with malice or reckless indifference. The maximum amount of compensatory and punitive damages per individual is $300,000 (scaled based on size of employer).

> ***BUCK COMMENT.*** *The remedies under Title II are more substantial than under Title I. Since employee benefit plans are likely to be viewed as part of an employee's "compensation" or as a "term and condition of employment," there has been concern among employers that if their group health plans or insurers were to discriminate based on genetic information in enrollment, eligibility, premiums, etc. (all of which are regulated under Title I), these actions could be deemed violations of Title II as well. Title II includes firewall language to the effect that a violation under Title I will not implicate enforcement actions or penalties under Title II.*

Effective Date

Title I is effective for plan years beginning after May 21, 2009. Thus, for calendar year plans, the genetic nondiscrimination provisions for health plans are effective for plan years plans beginning on January 1, 2010. Title II, prohibiting genetic nondiscrimination in employment, is effective November 21, 2009.

Conclusion

Although most employers and plan sponsors are already aware of the sensitivity of generic information and are generally in compliance with the new law, they should nevertheless review their health plan and employment practices to ensure they are not inappropriately requesting or receiving genetic information about employees or their family members. Buck's consultants are available to discuss the new law with you and assist in your review.