Recent Legislation Prohibits Genetic Discrimination

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On April 24, 2008, the Senate unanimously approved the Genetic Information Nondiscrimination Act ("GINA"), with subsequent approval by the House of Representatives on May 1, 2008. GINA prohibits employers and health insurance companies from discriminating against an individual based upon genetic testing. The bill was forwarded to the White House for the President's signature, which occurred on May 21, 2008.

More specifically, GINA prohibits employers and health insurers from making employment decisions or adjusting benefits based solely upon an individual's likelihood of acquiring a genetic disorder. In its findings, Congress notes, "New knowledge about genetics may allow for the development of better therapies that are more effective against disease or have fewer side effects than current treatments." However, Congress also notes, "These advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment" as this form of discrimination has been evident since the 1970's.²

GINA amends the Employee Retirement Income Security Act of 1974 ("ERISA") by explicitly prohibiting group-based discrimination on the basis of genetic information or predisposition. Further, a health insurance carrier may not adjust premiums or contribution amounts for the group plan on the basis of genetic information.

GINA also amends ERISA by placing limitations on requesting or requiring genetic information. A health insurance carrier may request, but not require a participant to undergo genetic testing if the following conditions are met: the request is made in writing; the insurer clearly indicates that the compliance is voluntary and non-compliance will have no effect on enrollment status or premiums or contribution amounts; the genetic information shall not be used for underwriting purposes; and the appropriate government notifications are made.

In this context, genetic testing means an analysis of human DNA, RNA, chromosomes, proteins or metabolites that detects genotypes, mutations or chromosomal changes. Genetic testing does not include testing for disease, disorders or pathological conditions that could be reasonably detected by a health care professional with appropriate training and expertise in the field of medicine involved.

Continuing, a health insurance carrier shall not adjust premium or contribution amounts for a group or for an individual on the basis of genetic information, pre-disposition or pre-existing condition concerning the group, the individual or an individual's family member. Genetic information includes genetic tests, the manifestations of a disease or disorder, but does not include any information about the age or sex of an individual.

¹ www.shrm.org/government/update/050208_1.asp

² H.R. 493.

Penalties may be assessed for noncompliance and said penalties may be increased for violations that are not *de minimus*.

GINA also details prohibitions of employment discrimination on the basis of genetic information. Generally speaking, employees of state agencies and employees of employers covered by Title VII of the Civil Rights Act of 1964 are covered by this legislation.

It shall be an unlawful employment practice for an employer to fail or refuse to hire or discharge any employee, or otherwise discriminate with respect to compensation, terms, conditions or privileges of employment because of genetic information with respect to an employee. Likewise, it is unlawful to limit, segregate or classify employees in any way that would deprive any employee of employment opportunities, based upon genetic information.

Employers are also prohibited from requesting, requiring or purchasing genetic information of an employee or an employee's family member, except where such requests are made inadvertently through a wellness program, when the employee provides written authorization, where the information is requested to comply with the Family & Medical Leave Act ("FMLA") or similar state requirements, where the employer purchases documents that are commercially and publically available that include family medical history; where the information is used for monitoring of the biological effects of toxic substances in the workplace; or where the employer conducts DNA analysis for law enforcement purposes and such testing is used for quality control purposes.

In situations where an employer possesses genetic information about an employee, such information shall be maintained on separate forms and in separate medical files and shall be treated as a confidential medical record of the employee.

Employers may disclose genetic information in limited situations. Specifically, employers may disclose genetic information at the written request of the employee, to an occupational or other health care provider if the research is conducted in compliance with Federal regulations, in response to a court order, to government officials, in compliance with the provisions of FMLA, or to a federal, state or local health agency.

Damages, costs and fees may be assessed for an employer's noncompliance. Further, no person shall be discriminated against because an individual opposes any act or practice made unlawful by GINA.

The effective dates of the legislation vary by section. Generally speaking, the employment provisions of GINA become effective in November 2009, and the provisions pertaining to group health plans become effective in May 2009.

In summary, the GINA legislation should continue to be monitored to ensure companies begin the process of revising health insurance policies, documents and employment practices in advance of the effective date. Employers should also properly update policies and procedures to address the prohibition of discriminatory practices based upon genetic information. Mr. Baker may be contacted with questions or concerns regarding compliance with this issue. He is also available to assist in the revision/drafting of policies.