

GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008

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ON

THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008

The Genetic Information Nondiscrimination Act of 2008 (GINA), signed into law May 21, 2008, provides broad protections for individuals with respect to the use of genetic information by group health plans and employers. This paper addresses the purpose of the three-part law followed by a detailed discussion of what the law entails and concludes with a summary and reference list.

PURPOSE

The following is a summary of the Genetic Information Nondiscrimination Act of 2008 (GINA) that provides general information regarding new legislation that amends existing Equal Employment Opportunity policies. Title I of GINA amends the Employee Retirement Income Security Act of 1974, the Health Insurance portability Act, and the Internal Revenue Code to prohibit genetic discrimination by group health issuers and group health insurance companies with respect to eligibility and premium contributions. Title II corresponds with Title VII of the Civil Rights Act of 1964 as amended and prohibits employers from using genetic information as a basis for discrimination against an individual with respect to employing, terminating, or other terms and conditions of employment. Title III amends child labor laws and includes miscellaneous provisions. The Act requires full compliance by employers with 15 or more employees, employment agencies, labor unions, joint labor-management training programs, and all federal employees.

The Equal Employment Opportunity Commission (EEOC) is responsible for developing and issuing regulations for the implementation of Title II of this Act by November 21, 2009. Currently, EEOC is in the process of incorporating inputs from various government agencies in an effort to faithfully apply all provisions of the Act consistent with Congress's intent. One of the first action items was a proposal by EEOC to propose rules under GINA to amend procedural and administrative regulations that include references to "GINA" along side references to the Civil Rights Act of 1964 Title VII and the American Disabilities Act in all future EEO Acts. The Commission has taken this opportunity to modernize outdated vocabulary by replacing "handicap" and "handicaps" with "disability" and "disabilities" throughout its regulations in Title 29 of the Code of Federal Regulations.

The Department of Health and Human Services (HHS) is responsible for ensuring federally supported institutions engaged in human research studies provide written assurance acceptable to the department or agency head stating that the institution will comply with all requirements stated in Section Title 45, Part 46.103, Protection of Human Subjects. However, an HHS Internal Review Board, also referred to as an independent ethics committee, must first approve activities prior to the commencement of a study. Sample collection methods may consist of either non-invasive techniques to include but not limited to educational tests, surveys, interviews, observations with certain restrictions or by collecting pathological samples.

DISCUSSION

- The Genetic Information Nondiscrimination Act of 2008 (GINA) signed into law May 21, 2008 provides broad protections for individuals with respect to the use of genetic information by group health plans and employers
- Title I prohibits discrimination based on genetic information with respect to health insurance and employment
 - Amends the Employee Retirement Income Security Act of 1974 (ERISA), Public Health Services Act (PHSA), and Internal Revenue Code (IRC)
 - Prohibits group health plans from requesting or requiring an individual or family member of an individual from undergoing a genetic test
 - Provides that prohibitions cannot limit the authority of a health care professional to request an individual to undergo genetic test or prevent a group health plan from attaining or using the results of a genetic test to make a determination regarding payment
 - Requires a health plan to request only the minimum amount of information necessary to accomplish the intended purpose
 - Allows a group health plan to request, but not require, an individual or family member to undergo genetic test for research purposes if the following requirements are met
 - Health plan must clearly indicate that compliance is voluntary and that noncompliance has no effect on enrollment status, premium or contribution amounts
 - No genetic information collected or acquired is used for underwriting purposes
 - Health plan must notify the Secretary of Health and Human Services (HHS) that it is conducting activities pursuant to this exception and includes a description of activities.
 - Prohibits a group health plan from requesting, requiring, or purchasing genetic information for underwriting purposes or as a condition for enrollment
 - Incidental obtainment of genetic information by the group health plan does not constitute a violation
 - Reference to genetic information of an individual or family member includes genetic information of a fetus carried by a pregnant woman and an embryo legally held by an individual utilizing an assisted reproductive technology
 - Applies prohibitions and conditions to all group health plans, large and small
 - Authorizes a penalty against a group health plan for failure to meet requirements of this Act

- Allows a waiver or limitations of penalties if failure was due to reasonable diligence
- Prohibits health insurance issuers offering coverage in the individual market (private insurance policy purchased by an employee) from establishing eligibility rules for enrollment
 - Ineligibility cannot be based on genetic information
 - Denial of service based on a pre-existing condition is disallowed
 - Requirements apply to nonfederal government plans
- Prohibits a Medicare supplemental policy from denying or conditioning issuance or effectiveness of the policy based on genetic information or pre-existing condition
 - Disallows requests or requirements for an individual or a family member to undergo genetic test
 - Bars requesting, requiring or purchasing genetic information for underwriting purposes or as a precondition for any individual prior to enrollment
 - Bans discrimination in the pricing of a policy or adjustments to premium rates
- Requires the Secretary of Health and Human Services to revise the Health Insurance Portability and Accountability Act of 1996
 - Mandates genetic information to be treated as health information
 - Prohibits use or disclosure by a group health plan, health insurance coverage or Medicare supplemental policy of genetic information for underwriting purposes
- Requires the Secretaries of Health and Human Services, Labor, and the Treasury to ensure regulations, rulings, and interpretations of this law are administered to have the same effect at all times and to adopt a coordinated enforcement strategy
- Title II prohibits employment discrimination on the basis of genetic information
 - Prohibits the practice by an employer, employment agency, labor organization, or joint labor-management committee, here after collectively referred to as “the employment system”, to discriminate against an employee, individual, or family member based on genetic information
 - Employers may not discharge or fail to hire an employee or otherwise discriminate against an employee with respect to compensation, terms, conditions, or privileges
 - Employment agencies may not refuse or fail to refer an individual for employment

- Labor organizations may not exclude or expel a member of the organization
- Employment agencies, labor organizations, or joint labor-management committees may not cause or attempt to cause an employer to discriminate against a member
- “The employment system” may not discriminate against an individual during admission to, or employment in programs that provide apprenticeship or other training or retraining opportunities
- Prohibits “the employment system” to limit, segregate, or classify employees, individuals, or members based on genetic information
 - Must not deprive or tend to deprive individuals of employment opportunities
 - Must not adversely affect status as an employee
- Prohibits “the employment system” from requesting, requiring, or purchasing an employee's genetic information, except for specific purposes
 - “The employment system” may request or require genetic information to comply with certification requirements of family and medical leave laws
 - Information is to be used for genetic monitoring of biological effects of toxic substances in the work place
 - “The employment system” may conduct DNA analysis for law enforcement as a forensic lab or for purposed of human remains identification
 - Use of genetic information is limited to analysis of DNA identification markers for quality control or detection of sample contamination
- Requires “the employment system” in possession of any genetic information about an employee to safeguard information in separate files and treat such information as a confidential medical record
- Prohibits “the employment system” from disclosing such genetic information except
 - To the employee or member upon request
 - To an occupational health or other health researcher
 - In response to a court order
 - To government officials investigating an employee’s compliance with certification provisions of the family and Medical Leave Act of 1993 (FMLA) or equivalent state FMLA requirements

- To a public health agency
- Sets requirements for enforcement of this Act
 - Provided that disparate (unequal) impact on the basis of genetic information does not establish cause of action under this Act
- Establishes the Genetic Nondiscrimination Study Commission six years after enactment of this Act to review the developing science of genetics
- Makes recommendations to Congress regarding whether to provide a disparate impact cause of action under this Act
- Title III contains miscellaneous provisions
 - States that if any provision, amendment, or the application of this Act is determined to be unconstitutional, the remainder of the Act will not be affected
 - Amends the Fair Labor Standard Act (FLSA) of 1938 to increase the maximum penalty for employers who violate oppressive child labor laws or certain child labor safety requirements
 - Establishes additional civil penalties for violation that cause permanent or substantial impairment to a bodily member, organs, mental faculty, or death to an employee under the age of 18
 - Increases the maximum penalty for any repeated or willful violation of the minimum wage or maximum hour requirements for employees

SUMMARY:

Title I of the Genetic Information Nondiscrimination Act of 2008 prohibits discrimination based on genetic information in health coverage and employment. Title II prohibits employment discrimination on the basis of genetic information. Title III preserves the integrity of the Act against contestation and updates child labor laws. The law requires full compliance by employers with 15 or more employees, employment agencies, labor unions, joint labor-management training programs, and all federal employers. The Act charges the Equal Employment Opportunity Council with issuing finalized regulations by November 21, 2009. GINA is unique in that it protects all Americans equally, transcending race, religion, gender, national origin, and sexual orientation.

References:

Genetic Information Nondiscrimination Act of 2008, H. R. 493, 110 Cong, 28 Sess. (2009)

Full Text of the Final Version of the GINA Bill as signed into Law May 21, 2008

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