

## Summary of the Genetic Information Nondiscrimination Act

May 21 2008— After being subject to more than a decade of Congressional debate, the Genetic Information Nondiscrimination Act of 2008 (P.L. 110-233) prohibits health insurers and employers from discriminating on the basis of genetic information, was signed into law by President Bush. The Act, which has received widespread, bipartisan support from policy makers and health insurance industry leaders alike, was passed unanimously in the Senate, and passed in the House with an overwhelming majority vote of 414 to 1.

The purpose of the legislation is to protect individuals from discrimination by health insurance and employers on the basis of an individual's genetic information. Additionally, the legislation aims to encourage those who could benefit from genetic testing, new technologies, and new genetic therapies to make use of these scientific advances, by mollifying fears of insurance and employment discrimination that could potentially result from participating in such health-promoting activities. As the field of behavioral and psychiatric genetics burgeons and more is learned about the genetic determinants of mental health, the Genetic Information Nondiscrimination Act establishes vital protections for those and family members of those with mental illness.

The legislation accomplishes this by:

- prohibiting insurance premium adjustment and enrollment restrictions on the basis of genetic services or predispositions
- precluding health insurers from requiring or requesting that an individual undergo genetic testing
- including all group health insurance programs, including state-regulated and individual insurance policies.
- prohibiting discriminatory employment practices, such as dismissing or failing to hire and individual based upon genetic information

Many states have already enacted legislation protecting individuals from genetic discrimination, and the Act does not preclude the establishment of more protective genetic nondiscrimination legislation. The Act establishes a national standard of protection, while allowing states who already have and who wish to implement stronger protections through state legislation to do so.

### **Genetic Information Covered**

The Act takes an expansive view of genetic information, as it includes under the definition of genetic information not only genetic test results specific to an individual, but also test results and the manifestation of disease in an individual's dependants and family members, due to the potential or assumed heritability of such disorders. Additionally, protections of the Act apply to the genetic information of an embryo or fetus carried by a pregnant woman or legally held by an individual while utilizing assisted reproductive technology.

## **Amendments to Current Law**

### ***Insurance***

#### *Employee Retirement Income Security Act of 1974 (ERISA)*

The Act amends the Employee Retirement Income Security Act to prohibit group health plans from requesting, requiring, or purchasing genetic information for the purposes of underwriting, in addition to prohibiting the adjustment of premium or contribution amounts for a covered group based upon knowledge of group member genetic information. The Act also prohibits health insurers from requiring that individuals undergo genetic testing. However, the Act does not disallow insurers to request the minimum amount of information about genetic testing necessary to determine payment for these services.

#### *Public Health Service Act (PHSA)*

The Genetic Information Nondiscrimination Act both amends the Public Health Service Act to provide protection for individuals covered through group health plans as it does the Employee Retirement Income Security Act, and extends this protection to individuals purchasing health coverage in the individual market from genetic discrimination. The Act prohibits health insurers offering health insurance in the group and individual market from establishing eligibility rules for enrollment based upon genetic information, prohibits the setting of premium rates based upon genetic information, and prohibits health insurance issuers in both the group and individual markets from requesting or requiring genetic testing for individuals or family members of individuals receiving coverage.

#### *Internal Revenue Code of 1986*

The act amends the Internal Revenue Code to prohibit group based discrimination on the basis of the genetic information of a group, such as the adjustment of premiums or contribution amounts. The Internal Revenue Code is also amended to proscribe the request, requirement, or purchase of genetic information prior to enrollment in a group health plan.

#### *Social Security Act*

The Genetic Information Nondiscrimination Act amends title XVIII (Medicare) of the Social Security Act to ensure that the same protections extended by the Public Health Service Act and The Employee Retirement Income Security Act to individuals covered by Medicare supplemental policies. Insurers offering Medicare supplemental policies are prohibited from discriminating in the pricing of the policy or adjusting premium rates, as well as denying or conditioning the issuance of the policy (such as exclusion of benefits based upon preexisting conditions), based upon genetic information. Additionally, insurers offering Medicare supplemental policies are not allowed to request or require genetic testing of covered individuals and their family members, as well as requesting or requiring genetic information for underwriting purposes.

The Act also amends title XI of the Social Security Act to require the Secretary of Health and Human Services to revise the Health Insurance Portability and Accountability Act of 1996 to and prohibit the disclosure or use of group health plans, health insurance coverage, or Medicare supplemental policy of and individual's genetic information for underwriting purposes. In order to do this, HIPPA will also be revised to include genetic information as part of the health information covered under the law.

## **Further Provisions**

### *Employment*

The Genetic Information Nondiscrimination Act protects individuals from employment discrimination by employers, employment agencies, labor organizations, of joint labor-management committee on the basis of genetic information, by prohibiting a number of discriminatory employment practices. The Act prohibits employers from failing or refusing to hire, discharging, or otherwise to discriminating against any employee (such as discriminatory compensation, terms, conditions, or privileges of employment) based upon genetic information. The Act also proscribes employment agencies from failing to or refusing to refer an individual for employment based upon genetic information, and prohibits labor organizations from excluding or expelling a member from membership based upon genetic information.

In addition to the above protections, the Genetic Information Nondiscrimination Act prohibits employers, agencies, or labor organizations from requesting, requiring, and purchasing an individual's genetic information, unless the information is required in order to comply with medical and family leave laws, in order to monitor the biological effects of toxic substances present in the workplace, or if an employer conducts genetic analyses in a forensic lab, for law enforcement purposes.

If an employer, employment agency, or labor organization does possess genetic information about an employee, the Genetic Information Nondiscrimination Act requires such information to be treated as confidential medical information, maintained in separate, confidential files. Additionally, the Act proscribes employers, agencies, or organization from disclosing such information, except upon request by the individual, occupational health researcher, public health agency, and government official investigating compliance to the Act, or in connection with compliance with family and medical leave laws.

## **Exceptions**

### *Health Care Professionals*

The Act does not limit the authority of a health care professional providing health care to an individual from requesting that that individual undergo genetic testing or services.

### *Manifested Disease*

Although the Act covers an individual's genetic test results that are predictive of future disease, the Title I of the Act does not preclude health insurers from utilizing and discriminating based

upon genetic test results directly related to manifested disease. However, Title II of the Act does prohibit employers from utilizing genetic information about an individual's manifested disease to discriminate against individuals, but not medical information that is not genetic information about manifested disease.

### *Other Insurance Plans*

The protections provided by the Act only apply to health insurance plans and employment settings, and not to other types of insurance. These may include long-term disability insurance, life insurance, short-term disability insurance, among others.

### *Research*

The Act does not prohibit the solicitation of genetic information from individuals or family members for the purposes of research, however, in order for a group health plan or employer to request genetic information for research, several conditions must be met.

### *Genetic Monitoring*

The act does not prohibit employers from utilizing genetic testing to assess the biological impact and effects of exposure to toxic substances. However, in order for employers to do so, written notice must be provided to employees, and employees must provide written authorization for the testing. Also, employees must be informed of the results, and employers must comply with federal genetic monitoring regulations. Finally, the employer must receive aggregate employee results, as to protect the identity of specific employees.

### *Payment*

The Act also does not preclude group or individual health plans from obtaining and utilizing the results of genetic tests for determining payment for such tests.

## **Enforcement**

The Act has amended both the ERISA and PHSA to provide general enforcement authority to the Secretary of Labor, Secretary of the Treasury, and the Secretary of Health and Human Services, and penalties will be assessed to those in noncompliance with the law. The general penalty for failure to abide by is \$100 per participant per day in noncompliance with the Act.

## **References**

Genetic Information Nondiscrimination Act of 2008 (PL-110-233)

Congressional Research Service (2008) CRS report for Congress: Genetic information nondiscrimination act (GINA). Washington, DC: Jones, N. L. & Sarata, A. K.