Report of the House Committee on Education and Labor

Genetic Information Nondiscrimination Act of 2007, HR 493

I. PURPOSE

The purpose of this legislation is to protect individuals from discrimination in health insurance and employment on the basis of genetic information. Establishing these protections will allay concerns about the potential for discrimination and encourage individuals to participate in genetic research and to take advantage of genetic testing and new therapies. The legislation will provide substantive protections to those individuals who may suffer from actual genetic discrimination now and in the future. These steps are essential to fulfilling the promise of the human genome project and improving the health and longevity of the American people.

II. COMMITTEE ACTION INCLUDING LEGISLATIVE HISTORY AND VOTES IN COMMITTEE

104TH-108TH CONGRESSES

Congresswoman Louise Slaughter introduced the first genetic information bill during the 104th Congress. The Genetic Information Nondiscrimination in Health Insurance Act of 1995, H.R. 2748, garnered 76 cosponsors.

During the 104th, the Senate Committee on Health, Education, Labor and Pensions began to hold hearings on the topic. The first hearing examined the public policy implications of advances in genetics research. In 1996, the Congress took a first step toward passing comprehensive genetic nondiscrimination legislation as part of the Health Insurance Portability and Accountability Act (HIPAA). HIPAA was signed into law in 1996 (P.L. 104-191; August 21, 1996). It prohibits discrimination against an individual in a group based on health status, including genetic information, and it primarily applies to group health plans and health insurance issuers in the group market.

Congresswoman Slaughter reintroduced the Genetic Information Nondiscrimination in Health Insurance Act in the 105th Congress as H.R. 306 with 213 cosponsors. Mrs. Slaughter filed a Motion to Discharge Committee on 6/11/1998 (Petition No: 105-4), but the motion was not considered.

In the 106th Congress, Congresswoman Slaughter introduced the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, H.R. 2457, on July 1, 1999 and garnered 164 cosponsors. The bill was reintroduced in the 107th Congress on February 13, 2001, as H.R. 602 with 266 cosponsors.

108TH CONGRESS

The Genetic Nondiscrimination in Health Insurance and Employment Act, H.R. 1910, was introduced by Congresswoman Slaughter on May 1, 2003 and garnered 242 cosponsors. The bill was referred to the Committees on Education and the Workforce, Energy and Commerce and Ways and Means. The Subcommittee on Employer-Employee Relations of this Committee held a hearing on `Genetic Non-Discrimination: Examining the Implications for Workers and Employers' on July 22, 2004. Witnesses testifying included: Dr. Kathy Hudson, Director, The Genetic and Public Policy Center, Johns Hopkins University, Washington, DC; Dr. Jane Massey Licata, partner, Licata & Tyrell, Marlton, New Jersey; Lawrence Lorber, partner, Proskauer Rose, on behalf of the US Chamber of Commerce, Washington, DC; and Tom Wildsmith, chairman, Genetic Testing Taskforce, American Academy of Actuaries, Washington, DC.

109TH CONGRESS

The Genetic Information Nondiscrimination Act of 2005, H.R. 1227, was introduced by Congresswoman Judy Biggert on March 10, 2005 and garnered 244 cosponsors. No action was taken in the House during the 109th Congress.

110TH CONGRESS

The Genetic Information Nondiscrimination Act of 2007, H.R. 493, was introduced by Congresswoman Slaughter on January 16, 2007. The bill has 205 cosponsors. The bill was referred to the Committees on Education and Labor, Energy and Commerce and Ways and Means. The Subcommittee on Health, Employment, Labor and Pensions held a hearing on January 30, 2007. The witnesses included: Congresswoman Louise Slaughter; Congresswoman Judy Biggert; Karen Rothenberg, Dean and Marjorie Cook Professor of Law, University of Maryland School of Law, Baltimore, MD; David Escher, former employee, Burlington Northern Santa Fe Railroad, Reno, NV; Harriet Pearson, Vice President, Corporate Affairs and Chief Privacy Officer, IBM Corporation, Washington, DC; and Burton J. Fishman, Partner, Fortney Scott, Genetic Information Nondiscrimination in Employment (GINE) Coalition, Washington, DC.

FULL COMMITTEE MARK-UP OF HR. 493

On February 14, 2007, the Committee on Education and Labor convened to markup H.R. 493, the Genetic Information Nondiscrimination Act. An amendment in the nature of a substitute was offered by Chairman Miller. An amendment to coordinate the recordkeeping requirements for genetic information with other laws was offered by Mr. Kline and accepted by unanimous consent. An amendment to specify application of the bill to a `child to be born' offered by Reps. Wahlberg and Hoekstra was defeated by a vote of 20 to 27. The Committee voted to report favorably H.R. 493 by voice vote.

III. SUMMARY OF THE BILL

THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2007

TITLE I--GENETIC NONDISCRIMINATION IN HEALTH INSURANCE

The legislation applies to employer-sponsored group health plans, health insurance issuers in the group and individual markets, Medigap insurance, and State and local non-federal governmental plans.

Nondiscrimination in enrollment and group premiums

Group health plan protections

The Employee Retirement and Security Act (ERISA) currently prohibits a group health plan or health insurance issuer offering coverage in connection with a group health plan from discriminating against an individual in the group in setting eligibility or premium or contribution amounts based on the individual's genetic information.

This legislation clarifies that genetic information includes `information about a request for or a receipt of genetic services by an individual or family member of such individual.' It also prohibits a health insurance issuer offering health coverage in connection with a group health plan from adjusting premium or contribution amounts for a group on the basis of genetic information concerning an individual in the group or a family member of the individual.

Individual health insurance market protections

The bill prohibits health insurance issuers in the individual market from using genetic information about enrollees or their family members to adjust premium or contribution amounts, using genetic information as a condition of eligibility for insurance coverage.

Medicare supplemental protections

The bill prohibits an issuer of a Medicare supplemental policy from denying or conditioning the issuance of a policy, or discriminating in the price of the policy, based on genetic information.

Limitation on requesting or requiring genetic testing

Group health plans, health insurance issuers in the group and individual market, and issuers of Medicare supplemental policies covered under this Title are prohibited from requesting or requiring an individual to take a genetic test. The legislation makes it clear that this provision is not intended to interfere with the delivery of health care services. For instance, the provision does not limit the authority of the treating health care professional to request that an individual or family member undergo a genetic test. Nor does it limit the authority of a health care professional who is employed by or affiliated with a health plan or issuer from notifying an individual about genetic tests or providing information about a genetic test, if such actions are carried out as part of a bona fide wellness program. However, the legislation does prohibit a health care professional from

requiring that an individual undergo a genetic test.

Privacy and confidentiality of genetic information

The HHS Standards for Privacy of Individually Identifiable Health Information (medical privacy regulations) (45 CFR Parts 160 and 164; final rule) protect the use and disclosure of all individually-identifiable health information, including genetic information. However, a permitted `use' of health information under the privacy rules (i.e., a specific item under `health care operations') is underwriting, a practice that is inherently discriminatory. HR 493 expressly bans the use or disclosure of genetic information for purposes of underwriting. In addition, the bill bans health plans and insurance issuers from collecting (i.e., requesting or requiring) genetic information in the first place for purposes of underwriting.

The bill further protects the privacy of genetic information by prohibiting plans and insurance issuers from collecting (i.e., requesting, requiring, or purchasing) genetic information prior to enrollment under the plan.

Enforcement

Title I generally uses the same mechanisms to enforce the protections established under this legislation as apply to other violations of these underlying statutes (i.e. the Employee Retirement Income Security Act (ERISA), Public Health Service Act (PHSA), and Social Security Act). In addition, the bill ensures that similarly situated individuals are provided the same protection under the law, regardless of whether they are currently sick or disabled, or currently healthy. All individuals (healthy and sick) have genetic information that could be used to discriminate against them.

With respect to the nondiscrimination requirements, the bill is based on the same penalty and enforcement structure as Title I of HIPAA, which addresses insurance portability and discrimination based on health-status. Aggrieved participants may seek redress either from the Secretary of Labor or the courts.

In addition, for group health plans and health insurance issuers in the individual and group markets, the appropriate Secretary may impose penalties of $100 per day/per person, with a minimum penalty of $2,500--up to $15,000 for multiple violations that are more than de minimis with an outside cap of up to $500,000 for a violation of the protections against genetic discrimination.

With regard to the privacy provisions established by this legislation, the same enforcement structure and penalties created by the Social Security Act for the HHS privacy standards. Under this legislation, the genetic privacy provisions are enforced by the HHS Office of Civil Rights. The Secretary of HHS may impose civil monetary penalties of $100 per violation--up to $250,000 and 10 years in prison for violations committed for commercial advantage, personal gain, or malicious harm.

TITLE II--PROHIBITING EMPLOYMENT DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION

Prohibition on discrimination

The legislation prohibits the use of genetic information in employment decisions, such as hiring, firing, job assignments, and promotions. This prohibition extends to employers, unions, employment agencies, and labor-management training programs.

Limitation on acquisition

Employers, labor organizations, employment agencies, and joint labor-management committees are prohibited from requesting, requiring, or purchasing genetic information about an employee or family member, except for the following legitimate reasons: (1) for genetic monitoring of biological effects of toxic substances in the workplace, (2) if the employer provides genetic services, such as through a wellness program, with the employee's prior consent, or (3) for compliance with the certification provision of the Family and Medical Leave Act or its state equivalent. The purchase of commercially and publicly available documents or inadvertently requesting or requiring family medical history would not violate this title. Under each of these exceptions, however, the genetic information still could not be used or disclosed.

Confidentiality protections

The legislation safeguards the confidentiality of genetic information in the employment setting. If an employer (acting as an employer) acquires genetic information, such information shall be treated and maintained as part of the employee's confidential medical records. Moreover, such information shall not be disclosed except in limited situations, such as to the individual or in order to comply with the certification provisions of Federal or State family and medical leave laws, or a court order.

Enforcement

The legislation protects applicants or employees of employers defined under the Civil Rights Act of 1964 (42 U.S.C. 2000e(f)), State employees, Federal employees, Congressional employees, and employees as defined in 3 U.S.C. 411(c)0. Aggrieved individuals are required to file a charge with the appropriate enforcement agency within a certain time period, prior to filing a suit in court. The bill provides for the same compensatory and punitive damages available to prevailing plaintiffs under 42 U.S.C. 1981a.

Disparate impact

The bill does not cover claims based on disparate impact and establishes a commission to review the science of genetics and advise the Congress on the need for establishing a separate disparate impact cause of action in the future.

DEFINITIONS--(GENERALLY APPLY TO BOTH TITLE I AND TITLE II)

Genetic information is defined to include information about an individual's genetic tests; the genetic tests of family members of the individual; or the occurrence of a disease or disorder in family members of the individual. Genetic information does not include information about the sex or age of an individual for purposes of this legislation.

Genetic test is defined as an analysis of DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes. A genetic test does not mean an analysis of (1) proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or (2) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved. The second exception to genetic test only applies to Title I of the legislation.

Genetic Services is defined as a genetic test; genetic counseling (including obtaining, interpreting, or assessing genetic information), or genetic education.

Family Member includes the spouse of an individual, a dependent child, and any other individual who is a first degree, second degree, third degree or fourth degree individual described above.

TITLE III--SEVERABILITY

If a court strikes down a provision of the bill, it shall not affect the legality of other provisions of the bill.

* * *

TEXT OF BILL AS AMENDED

(5) FAMILY MEMBER- The term `family member' means with respect to an individual-

      (A) the spouse of the individual;
      (B) a dependent child of the individual; and
      (C) any other individual who is a first-degree, second-degree, third-degree, or fourth-degree relative of an individual described in subparagraph (A) or (B).

(6) GENETIC INFORMATION-

      (A) IN GENERAL- Except as provided in subparagraph (B), the term genetic information' means information about--

            (i) an individual's genetic tests;

(ii) the genetic tests of family members of the individual; or

(iii) the occurrence of a disease or disorder in family members of the individual.

(B) EXCLUSIONS- The term `genetic information' shall not include information about the sex or age of an individual.

(7) GENETIC TEST-

(A) IN GENERAL- The term `genetic test' means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

(B) EXCEPTIONS- The term `genetic test' does not mean--

(i) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or

(ii) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.

(8) GENETIC SERVICES- The term `genetic services' means--

(A) a genetic test;
(B) genetic counseling (including obtaining, interpreting, or assessing genetic information); or
(C) genetic education.'.