



Legislative Bulletin.....May 1, 2008

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H.R. 493—Genetic Information Non-Discrimination Act (as amended)

H.R. 493—Genetic Information Non-Discrimination Act of 2007 *(Slaughter, D-NY)*

Order of Business: The Senate amendments to the bill are reportedly scheduled to be considered on Thursday, May 1, 2008, subject to a closed rule that provides for one hour of general debate on the Senate amendments and waives all points of order against the amendments (except those arising under PAYGO).

Summary: H.R. 493 would prohibit the use of genetic information by employers in employment decisions and by health insurers and health plans in making enrollment determinations and setting insurance premiums. The specific provisions of the bill as amended by the Senate are summarized below.

- Amends the Employee Retirement Income Security Act (ERISA), the Public Health Service Act, and the Internal Revenue Code to prohibit a group health plan, and a health insurance issuer offering group health insurance coverage in connection with a group health plan, from the following:
 - Adjusting premium or contribution amounts for the group covered under the plan on the basis of genetic information;
 - Requiring an individual or a family member to undergo a genetic test;
 - Requesting, requiring, or purchasing genetic information for underwriting purposes; and
 - Requesting, requiring, or purchasing genetic information with respect to any individual prior to that individual's enrollment under the plan or coverage in connection with their enrollment.

The bill allows for certain research exceptions to the above prohibitions.

- Defines an individual or a family member for purposes of this Act as:
 - The fetus inside of a pregnant mother; and
 - Any embryo legally held by the individual or family member (with respect to assisted reproductive technology).
- Defines genetic test as: “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.” The definition does not include the following:

- “An analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or
 - “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.”
- Imposes a penalty against any plan sponsor or group health plan for failure to meet requirements with respect to genetic information in connection with their health plan. The penalty would be \$100 each day in noncompliance with respect to each participant to whom such failure relates. Under certain circumstances, the penalty could not be less than \$15,000 per participant. In addition, the Secretary could waive the penalty under certain circumstances.
- Prohibits a health insurance issuer in the individual market from doing the following:
 - Establishing rules for the eligibility of any individual to enroll in individual health insurance coverage based on genetic information;
 - Adjusting premium or contribution amounts for an individual on the basis of genetic information concerning the individual or a family member;
 - Imposing any preexisting condition exclusion based on the basis of genetic information, with respect to their coverage;
 - Requesting or requiring an individual or family member to undergo a genetic test;
 - Requesting, requiring or purchasing genetic information for underwriting purposes; and
 - Collecting genetic information with respect to any individual prior to the individual’s enrollment under the plan.
- Prohibits an issuer of a Medicare supplemental policy from the following:
 - Denying or conditioning the issuance of a policy and from discriminating in the pricing of the policy of an individual on the basis of genetic information;
 - Requesting or requiring individuals to undergo genetic tests; and
 - Requesting, requiring, or purchasing genetic information during underwriting.
- Directs the National Association of Insurance Commissioners (NAIC) to modify its NAIC model regulations to mirror the above prohibitions required by this Act.
- Directs the Secretary of Health and Human Services to revise the Health Insurance Portability and Accountability Act (HIPAA) private regulations to be consistent with provisions in this Act, affecting the use of genetic information.
- Prohibits employers, employment agencies, and labor organizations from the following:
 - Refusing to hire an employee or discriminating against an employee because of genetic information related to that individual;
 - Limiting, segregating or classifying employees in any way that would deprive or adversely affect the status of the employee due to their genetic information; and
 - Requiring or purchasing genetic information, except in certain circumstances.
- Requires employers, employment agencies, and labor organizations to maintain any genetic information about employees or members as confidential, subject to certain exceptions.
- Provides for remedies with the Equal Employment Opportunity Commission (EEOC) against employers who engage in discriminatory employment practices with respect to their employees’ genetic information.

Additional Background on Senate Amendments: On March 4, 2008, 11 Senators, led by Sen. Tom Coburn (R-OK), sent a letter to Majority Leader Reid and Senate HELP Committee Chairman Kennedy outlining remaining conservative concerns regarding passage of the Genetic Information Non-Discrimination Act (GINA). A summary of those concerns, along with the ways in which the compromise language addressed the issues raised in the March 4 letter, follows below.

- Title I imposes requirements on health plans regarding insurance coverage, while Title II imposes requirements on employers regarding employment and related hiring decisions. Earlier drafts of the bill did not include language clarifying that group health insurance plan sponsors may not be subjected to the more expansive remedies provided by Title II, which provides for rulemaking by the Equal Employment Opportunity Commission (EEOC), and remedies before the same body and, ultimately, federal courts. This “firewall” provision was incorporated into the Senate agreement, which should ensure that the broader remedies available in Title II will be used only against employers who violate their employees’ civil rights, not for employees seeking to litigate group health plan disputes.
- The Senate agreement maintained language in the original House-passed bill ensuring that entities covered under the Health Insurance Portability and Accountability Act (HIPAA) privacy regulations can continue to communicate medical and genetic information consistent with the HIPAA statute without facing a separate and potentially conflicting regulatory regime under GINA.
- The Senate agreement also includes clear language excluding “manifested” diseases from GINA’s provisions. In general, health plans can receive information about whether an individual has a manifested disease, and these facts can be used during the underwriting process for individual and small group coverage in some states. By maintaining current law clarity, the agreement’s language would maintain long-established underwriting processes for already-occurring health conditions—while providing protections for genetic information for diseases not yet manifest in patients.
- Lastly, as a result of efforts by the Congressional Pro-Life Caucus, the Senate agreement maintained language in the House-passed bill extending GINA protections to any fetus carried by pregnant women or any embryos held by individuals or family members. Maintaining this language ensures that families will not have an economic incentive to abort their unborn children, fearing that they could be discriminated against due to results from prenatal testing. Groups such as Family Research Council and the National Conference of Catholic Bishops have endorsed the compromise Senate language for this reason.

To the extent that concerns still remain regarding the GINA language, they revolve primarily around the strength of the “firewall” language, and the lack of a general-purpose “business necessity” exemption for companies that may find a legitimate need to utilize genetic information for a reason not expressly authorized within the statute. Some business groups also

question whether and to what extent genetic non-discrimination legislation is necessary, particularly as insurers are currently prohibited from such discrimination. Nevertheless, the significant progress made on the concerns outlined by Sen. Coburn and his colleagues outweighed any lingering concerns, leading the Senate to approve the bill by a 95-0 vote.

Legislative History: H.R. 493 was introduced on January 16, 2007, and referred to the House Committees on Education and Labor, Energy and Commerce, and Ways and Means. The Education and Labor Committee held a mark-up and reported the bill, as amended, by voice vote on February 14, 2007. The Energy and Commerce Committee held a mark-up and reported the bill, as amended, on March 23, 2007. The Ways and Means Committee held a mark-up and reported the bill, as amended, by voice vote on March 21, 2007. The bill was passed on April 25, 2007, by a vote of 420-3. On April 24, 2008, the Senate passed the bill with an amendment by a 95-0 vote.

Cost to Taxpayers: According to CBO, enacting H.R. 493 “would increase the number of individuals who obtain health insurance by about 600 people per year, nearly all of whom would obtain insurance in the individual market. The bill would affect federal revenues because the premiums paid by some of those newly insured individuals would be tax-deductible.” As such, CBO estimates that the bill would reduce revenues by less than \$500,000 in each year from 2008 through 2017, by \$1 million over the 2008-2012 period, and by \$2 million over the 2008 through 2017 period.

In addition, CBO states that “the bill’s requirements would apply to Medicare supplemental insurance, which would affect direct spending for Medicare.” However, CBO estimates that the bill would have no significant effect on direct spending. Finally, CBO estimates that H.R. 493 would result in discretionary costs of less than \$500,000 in FY 2008, and \$2 million over the FY 2008 through FY 2017 period.

Does the Bill Expand the Size and Scope of the Federal Government?: Yes, the bill grants authority to the Secretaries of Health and Human Services, Labor, and Treasury to promulgate regulations and engage in enforcement activities with respect to the Title I provisions relating to health insurance coverage.

Does the Bill Contain Any New State-Government, Local-Government, or Private-Sector Mandates?: Yes. According to CBO, the bill would “preempt some state laws that establish confidentiality standards for genetic information, and would restrict how state and local governments use such information in employment practices and in the provision of health care to employees.” In addition, CBO explains that the bill “contains private-sector mandates on health insurers, health plans, employers, labor unions, and other organizations.” In both cases, however, CBO does not believe that the cost of the mandates would exceed thresholds established in the Unfunded Mandates Reform Act (\$66 million and \$131 million in 2007, respectively, adjusted for inflation).

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