



Senate Amendment to H.R. 493 - Genetic Information Nondiscrimination Act of 2007

EXECUTIVE SUMMARY

H.R. 493 was introduced by Representative Louise Slaughter (D-NY) on January 16, 2007. It was passed by the House, under suspension of the rules, by a vote of 420 to 3 on April 25, 2007. The Senate amended and passed H.R. 493 on April 24, 2008, by a vote of 95 to 0.

This original legislation prevents genetic discrimination in health insurance and the workplace, by prohibiting insurers from basing premium and coverage decisions on genetic information, as well as forbidding employers from hiring or firing individuals based on the same information.

The Senate amendment to H.R. 493 maintains many of the provisions previously passed by the House and includes a new "firewall" that prohibits individuals from suing their employers and insurers for the same violation. In addition, the Senate amendment includes rules of construction that provide insurers with clearer authority for using manifest disease information for underwriting purposes.

FLOOR SITUATION

The Senate Amendment to H.R. 493 will be considered under a closed rule on May 1, 2008. The rule:

- Provides for the consideration of the Senate amendment to H.R. 493
- Makes in order a motion by the chairman of the Committee on Education and Labor to concur in the Senate amendment.
- Waives all points of order against consideration of the motion except those arising under clause 10 of rule XXI.
- Provides that the Senate amendment and the motion shall be considered as read.
- Provides on hour of debate on the motion with 20 minutes equally divided and controlled by the chairman and ranking minority member of the Committee on Education and Labor; 20 minutes equally divided and controlled by the chairman and ranking minority member of the Committee on Energy and Commerce; 20 minutes equally divided and controlled by the chairman and ranking minority member of the Committee on Ways and Means.

This legislation was introduced by Rep. Slaughter (D-NY) on January 16, 2007. The bill was reported from the Committees on Education and Labor, Energy and Commerce, and Ways and Means. The House passed H.R. 493 on April 25, 2007, under suspension of the rules, by a vote of 420 to 3 ([Roll Call 261](#)). The Senate amended the bill and passed it on April 24, 2008, by a vote of 95 to 0 ([Record Vote 113](#)).

The House is expected to consider the Senate amended version of H.R. 493 on May 1, 2008.

BACKGROUND

Research into the human genome has resulted in a wealth of information such as specific genes that are linked to diseases such as Alzheimer's or Cancer. Further, studies of the human genome have led to the



development of tests to determine an individual's likelihood to have certain genetic diseases. Overall, understanding an individual's genetic makeup can lead to early detection and prevention of disease.

There is a concern that genetic information could be used by health insurers and employers to discriminate against those who are known to –or have the potential to- carry genes that increase their likelihood for developing cancer or other chronic diseases. This may cause individuals who have the hereditary potential of inheriting a disease to refrain from genetic testing, in order to keep their insurance; which could lead to even higher health costs, and deaths in the future due to genetic illnesses that could have been easily treated. Further, genetic discrimination could lead to a decrease in innovation and research due to a lack of participation.

The House passed H.R. 493 on April 25, 2007, by a vote of 420 to 3. The bill was then sent to the Senate where Senator Tom Coburn (R-OK) placed a hold on the bill because of concerns regarding provisions in the bill that could open employers to lawsuits under both insurance and employment laws. Upon reaching a compromise with Senate sponsors of the bill, Senator Coburn removed his hold and the bill passed 95 to 0 on April 24, 2008.

SUMMARY

The purpose of H.R. 493 is to prevent genetic discrimination in health insurance and the workplace, by prohibiting insurers from basing premium and coverage decisions on genetic information, as well as forbidding employers from hiring or firing individuals based on the same information.

Senate Amendment: The Senate amendment maintains many of the provisions previously passed by the House and includes a new “firewall” that prohibits individuals from suing their employers and insurers for the same violation. In addition, the Senate amendment includes rules of construction that provide insurers with clearer authority for using manifest disease information for underwriting purposes.

Summary of H.R. 493 as passed by the House on April 25, 2007

- Amend the Employee Retirement Income Security Act of 1974 (ERISA) and the Public Health Service Act to set penalties for health plans and insurers who discriminate in enrollment and premiums based on genetic information, as well as banning them from requiring genetic testing.

**Note: This strengthens the prohibition against discrimination by group health plans and health issuers in the group and individual markets on the basis of genetic information or services to prohibit genetic discrimination.*

- Amend title XVIII (Medicare) of the Social Security Act to prohibit issuers of Medicare supplemental policies from discriminating on the basis of genetic information.

**Note: Currently Medicare does not include language specifically prohibiting genetic discrimination.*

- Ban a group health plan, a health insurance issuer, or issuer of a Medicare supplemental policy from using or disclosing genetic information (including information about a request for or a receipt of genetic services by an individual or family member of such individual) for purposes of underwriting, determinations of eligibility to enroll, premium rating, or the creation, renewal or replacement of a plan, contract or coverage for health insurance or health benefits.



**Note: This is more restrictive than HIPAA because it extends medical privacy and confidentiality rules to the disclosure of genetic information and prohibits health plans from acquiring such information.*

- Bans employers, employment agencies, labor organizations, or training programs from discriminating against or depriving an individual of employment opportunities based on genetic information.
- Forbid the collection and disclosure of genetic information, with certain exceptions.
- Extend genetic information protections to fetus' in the case of woman who is pregnant.
- Establish a Genetic Nondiscrimination Study Commission to review the developing science of genetics and advise Congress on the impact of this Act.

**Note: The purpose of this commission is to evaluate for any disparate impact that has resulted from this legislation.*

- Require employers to keep genetic information separate from other employee health information;
- Establishes that if any provision of this Act, an amendment made by this Act, or the application of such provision or amendment to any person or circumstance is held to be unconstitutional, the remainder of this Act, the amendments made by this Act, and the application of such provisions to any person or circumstance shall not be affected thereby.

**Note: This is known as Severability.*

COST

“CBO estimates that enacting H.R. 493 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 2008-2017 period. (These estimates include reductions in off-budget receipts from Social Security payroll taxes of less than \$500,000 over the 2008-2012 period, and slightly less than \$1 million over the 2008-2017 period.) The bill's requirements would apply to Medicare supplemental insurance, which could affect direct spending for Medicare. However, we estimate that the bill would have no significant effect on direct spending.” ([CBO Cost Estimate](#))

STAFF CONTACT

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