

Senate OKs Protection for Genetic Data

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The Senate on a 95-0 vote April 24 passed the Genetic Information Nondiscrimination Act. House approval is expected next week, and the White House has indicated President Bush will sign the bill into law.

The legislation would prohibit discriminatory actions based on an individual's genetic data by employers and insurers. It also would require genetic information possessed by employers to be confidentially maintained and to be disclosed under tightly controlled circumstances.

Rules promulgated to implement the law following enactment could require specific steps to protect the confidentiality and integrity of genetic information in paper and electronic form. This would require significant changes in organizational processes of handing genetic information and in computer systems to secure the data.



Passage came shortly after bi-partisan members of the House and Senate agreed on provisions of the bill. Many organizations, operating under the Coalition for Genetic Fairness, have worked for 13 years to get legislation through Congress.

In efforts last year to get the bill passed, Sen. Edward Kennedy (D-Mass.) explained the need to his colleagues: "If Congress enacts clear protections against genetic discrimination in employment and health insurance, all Americans will be able to enjoy the benefits of genetic research, free from the fear that their personal genetic information will be misused," he said. "If Congress fails to make sure that genetic information is used only for legitimate purposes, we may well squander the vast potential of genetic research to improve the nation's health."

Other provisions of the bill, S. 358, as it passed the Senate include:

- * Prohibiting enrollment restrictions and premium adjustments on the basis of genetic information or services;
- * Preventing insurers under all types of health insurance programs from requesting or requiring an individual to take a genetic test;

* Prohibiting discrimination in hiring, compensation and other personnel issues based on genetic make-up; and

* Prohibiting collection of genetic information by employers and allowing genetic testing only to monitor adverse effects of hazardous workplace exposures.

Members of the Coalition for Genetic Fairness include the Genetic Alliance, Affymetrix, American Academy of Pediatrics, American Heart Association, American Society of Human Genetics, Brown University, Hadassah, National Society of Genetic Counselors, National Workrights Institute and the PKD Foundation. More information is available at geneticfairness.org.

Text of S. 358 as passed by the Senate soon will be available at congress.gov.

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