

Bill to ban genetics in underwriting insurance advances

Copyright. InsuranceTimes™ © 2003 by M&S Communications, Inc. All rights reserved. October 28, 2003

by Jim Abrams
Associated Press

WASHINGTON (AP) — Insurance companies would be barred from using people's genetic information or family histories to deny medical coverage or set premiums under a bill passed 95-0 by the Senate on last week.

Employers would also be prohibited from using such information in hiring and firing.

The measure, supporters said, would protect people who might be reluctant to undergo genetic testing for such diseases as breast cancer or Huntington's disease because they fear that information could be used against them.

"It simply isn't right that the very information which may lead to a healthier life and the prevention of a disease may also lead to the denial of health insurance, or higher rates," said Sen. Olympia Snowe, R-Maine, who has led a years-long effort to find a bipartisan consensus on the legislation.

"We can't afford to take one step forward in science, but two steps backward in civil rights," said Senate Democratic leader Tom Daschle of South Dakota, who worked with Snowe and others on the compromise proposal.

The bill, S.1053, which has yet to move in the House, builds on a 1996 law, co-authored by Sen. Edward Kennedy, D-Mass., that shields patient records from discriminatory use.

"A person's genetic secrets should be held in trust between individuals and their doctors, not used as a basis to deny that person health care coverage or to refuse to hire or promote them at work," said Kennedy.

Advances in genetics have made it possible to determine a person's predisposition to some cancers, glaucoma, cystic fibrosis and heart attacks, but have also raised ethical concerns about how that information is used.

Snowe cited a case where 32 percent of the women offered genetic testing for breast cancer by the National Institutes of Health declined because of fears of health insurance discrimination.

June Walker, president of the Jewish women's organization Hadassah, said her group has been pushing the issue since Hadassah medical facilities found a high frequency of Jewish women with genetic mutations predisposing them to some types of cancer, including breast and ovarian cancer. "But as science races ahead, individuals are hesitant to submit to genetic tests for fear of insurance and employment discrimination," she said.

But Dr. Donald Young, president of the Health Insurance Association of America, said the bill, if well-intended, was "unwise" because consumers are already adequately protected.

"Imposing restrictions beyond those already in place could hurt the very people they are intended to help by limiting the ability of insurers to appropriately and fairly set premiums," he said.

The legislation bars use of genetic information in employment decisions, including hiring, firing, job assignments or promotions. It also prohibits a company from collecting genetic data from an employee or family member except in special cases, such as monitoring the biological effects of toxic material in the workplace.

Insurers may not collect genetic information prior to enrolling a person in a plan or use that information to deny coverage or set premium rates.

Rep. Louise Slaughter, D-N.Y., has introduced similar legislation in the House that gives people greater ability to sue employers or insurers over discrimination. Slaughter urged the House to take up the Senate bill.

In the Senate bill, those claiming discrimination by an employer can take the case to the Equal Employment Opportunity Commission, as they would in a racial or sex discrimination case, and can file civil claims.

Also urging the House to move quickly was Dr. Francis Collins, head of the National Human Genome Research Institute, the National Institutes of Health agency leading the project that completed a map of the human genetic code.

A decade ago when he joined the NIH, genetic discrimination was already coming up "as an area that could cause this wonderful revolution fueled by the genome project to actually be stillborn because people would be afraid of getting the information that otherwise be of great advantage to them for medical purposes," he said.

House Education and the Workforce Committee Chairman John Boehner, R-Ohio, said he would hold hearings "to carefully consider this extremely complex area of law and science to ensure that worker privacy is sufficiently protected."

The administration has indicated its support for the bill.

But Neil Trautwein, a spokesman for the National Association of Manufacturers, said his group had mixed emotions about the Senate bill, noting that while it improved on Democratic-backed versions that make it easier to sue, "there is a manifest lack of a regulatory record of discrimination and we figure that this could become just another plank in employment litigation." □