

There have already been cases of discrimination as a result of an employer learning of an employee's genetic risk. In addition, cases have arisen where health insurance access was denied as a result of a genetic predisposition.

This is problematic because we are only in the first stages of understanding the human genome. Genetic testing has proven effective in some cases but it can be argued that the presence of a gene or certain genetic characteristics will not always result in the onset of the particular illness. The potential for discrimination is great. Although several States, including my own State of Oregon, have begun to address the issue of genetic information and health insurance, there are currently no Federal laws governing the use of genetic information.

The legislation that I am introducing today with my colleague, Senator MACK, is modeled on the Genetic Privacy Act recently passed by the Oregon Legislature. It also draws on recommendations made by the NIH-sponsored ELSI Working Group and the National Action Plan on Breast Cancer.

The purpose of the Genetic Privacy Act of 1995 is to establish some initial limitations with respect to the disclosure and use of genetic information with the goal of balancing the need to protect the rights of the individual against society's interests. The bill is intended as a first step—to ensure that there are some Federal standards in place in the most critical areas of concern. I see it as a working draft to be refined as the science progresses. The bill would define the rights of individuals whose genetic information is disclosed. In addition, it would protect against discrimination by an insurer or employer based upon an individual's genetic characteristics.

First, the bill prohibits the disclosure of genetic information by anyone without the specific written authorization of the individual. This disclosure provision could apply to health care professionals, health care institutions, laboratories, researchers, employers, insurance companies, and law enforcement officials. The written authorization must include a description of the information being disclosed, the name of the individual or entity to whom the disclosure is being made, and the purpose of the disclosure. This provision preserves the individual's ability to control the disclosure of his or her genetic information. There are several exceptions for the purposes of criminal or death investigations, specific orders of Federal or State courts for civil actions, paternity establishment, specific authorization by the individual, genetic information relating to a decedent for the medical diagnosis of blood relatives of the decedent, or identifying bodies.

Second, the legislation prohibits employers from seeking to obtain or use genetic information of an employee or prospective employee in order to discriminate against that person. In

March 1995, the U.S. Equal Employment Opportunity Commission [EEOC] released official guidance on the definition of the term "disability". The EEOC's guidance clarifies that protection under the Americans With Disabilities Act extends to individuals who are discriminated against in employment decisions based solely on genetic information. Issuance of the EEOC's guidance is precedent setting—it is the first Federal protection against the unfair use of genetic information. The provision included in the bill is intended to reiterate the ruling of the EEOC and make it clear that this practice would be prohibited under Federal law.

Third, the legislation prohibits health insurers from using genetic information to reject, deny, limit, cancel, refuse to renew, increase rates, or otherwise affect health insurance. This is in line with changes that are currently under consideration with regard to health insurance and preexisting condition exclusions.

A study of genetic discrimination prepared by Paul R. Billings, M.D. and cited by the NIH-DOE ELSI Working Group in their report entitled "Genetic Information and Health Insurance," indicates that there have been a number of cases of discrimination already as the result of an insurer learning of an individual's genetic predisposition. One woman who was found to carry the gene that causes cystic fibrosis was told she and her children were not insurable unless her husband was determined not to carry the cystic fibrosis gene. She went without health insurance for several months while this was determined. In another case, a man diagnosed with Huntington disease was denied health insurance on the basis that it was a preexisting condition, even though no previous diagnosis of Huntington had been made.

As the prevalence of genetic testing spreads, so does the risks of discrimination. Women found to carry the gene that indicates breast cancer susceptibility, BRCA1, fear they will lose health coverage if their insurer finds out. However, having this information may provide early treatment and prevention options for the woman. The provision relating to health insurance in the bill will provide much needed assurance to individuals with genetic predispositions. This will ensure that they will not risk losing their health coverage when they need it the most.

Finally, the bill requires the recently established National Bioethics Advisory Commission to submit to Congress their recommendations on further protections for the collection, storage, and use of DNA samples and genetic information obtained from those samples, and appropriate standards for the acquisition and retention of genetic information in all settings. This provision is intended to ensure that the social consequences of genome research are considered as the technology develops and not after the fact.

Madam President, as I said previously, this is a first step. This bill addresses the most pressing concerns surrounding genetic testing and the disclosure of genetic information as they relate to health insurer and employer discrimination. I believe this is a good beginning and I hope my colleagues will join me in supporting this important legislation. ●

ADDITIONAL COSPONSORS

S. 881

At the request of Mr. PRYOR, the names of the Senator from Virginia [Mr. WARNER], the Senator from Mississippi [Mr. COCHRAN], and the Senator from Indiana [Mr. COATS] were added as cosponsors of S. 881, a bill to amend the Internal Revenue Code of 1986 to clarify provisions relating to church pension benefit plans, to modify certain provisions relating to participants in such plans, to reduce the complexity of and to bring workable consistency to the applicable rules, to promote retirement savings and benefits, and for other purposes.

S. 949

At the request of Mr. GRAHAM, the names of the Senator from Georgia [Mr. NUNN], the Senator from Arkansas [Mr. BUMPERS], and the Senator from Kentucky [Mr. MCCONNELL] were added as cosponsors of S. 949, a bill to require the Secretary of the Treasury to mint coins in commemoration of the 200th anniversary of the death of George Washington.

S. 1028

At the request of Mrs. KASSEBAUM, the name of the Senator from Virginia [Mr. WARNER] was added as a cosponsor of S. 1028, a bill to provide increased access to health care benefits, to provide increased portability of health care benefits, to provide increased security of health care benefits, to increase the purchasing power of individuals and small employers, and for other purposes.

S. 1150

At the request of Mr. SANTORUM, the name of the Senator from Illinois [Mr. SIMON] was added as a cosponsor of S. 1150, a bill to require the Secretary of the Treasury to mint coins in commemoration of the 50th anniversary of the Marshall plan and George Catlett Marshall.

ADDITIONAL STATEMENTS

THE LIKELIHOOD OF A GATT CHALLENGE TO AN EMBARGO ON IRAN

● Mr. D'AMATO. Mr. President, I rise today to discuss the likelihood of a GATT challenge to an embargo on Iran.

On December 13, 1994, the Congressional Research Service did a Memorandum for Representative Peter DeFazio entitled "The Likelihood of a