

SENATE BILL REPORT

SB 5111

As Reported By Senate Committee On:
Health & Long-Term Care, February 17, 1999

Title: An act relating to health insurance discrimination on the basis of genetic information.

Brief Description: Prohibiting health insurance discrimination on the basis of genetic information.

Sponsors: Senators Franklin, Winsley, Thibaudeau, Wojahn, McAuliffe, Fraser, Prentice, Rasmussen, Kline, Brown, Eide, Bauer, Costa, Jacobsen, Spanel, Goings, Loveland, Gardner, Fairley, B. Sheldon and Kohl-Welles.

Brief History:

Committee Activity: Health & Long-Term Care: 2/8/99, 2/17/99 [DPS].

SENATE COMMITTEE ON HEALTH & LONG-TERM CARE

Majority Report: That Substitute Senate Bill No. 5111 be substituted therefor, and the substitute bill do pass.

Signed by Senators Thibaudeau, Chair; Wojahn, Vice Chair; Costa, Franklin, Johnson and Winsley.

Staff: Christopher Blake (786-7446)

Background: There is a global effort underway to map the entire human genetic structure by the year 2005. As the research has progressed, scientists have linked over 4000 diseases and disorders to genetic origins. Genetic links have been discovered for such illnesses as cystic fibrosis, hemophilia, Huntington's disease, sickle-cell anemia, and various forms of cancer.

The benefits of this research are available to humans through genetic tests which can tell an individual what their own genetic makeup is. Genetic tests are conducted by analyzing body or blood tissue to determine an individual's genetic composition. An individual who is aware of his or her genetic predisposition toward a particular illness may, in some cases, be able to postpone or lessen the effects of the disease through medicines, monitoring, or lifestyle changes. Genetic data can also assist couples in making informed family planning choices by telling them what conditions their children may face.

There is concern that health carriers may use the genetic information from these tests to remove individuals with a predisposition for high cost diseases from their policies. Congress passed the Health Insurance Portability and Accountability Act in 1996 which prohibits a group health plan from denying enrollment based on an individual's genetic information if the person has not yet been diagnosed with symptoms of the disease. In addition, 33 states have passed legislation further limiting insurance carriers' use of genetic test results in

denying applications, adjusting premiums, terminating, or not renewing coverage, or taking other adverse action.

Summary of Substitute Bill: A health carrier (health maintenance organization, health care service contractor, or disability insurer) may not deny or cancel health coverage, or vary premiums, terms, or conditions for health plan coverage on the basis of genetic information or because of a request for genetic services as defined in the act. Genetic information may not be disclosed without the consent of the individual. Genetic information may be used for approved research projects or by health care carriers for disease prevention screening. There is an exemption for the Department of Health's newborn screening activities.

Substitute Bill Compared to Original Bill: Disclosure of genetic information is allowed with the patient's consent for approved research projects. A health carrier is permitted to assemble a family history to be shared with family members for use in disease prevention programs. The Department of Health's newborn screening activities are exempt.

Appropriation: None.

Fiscal Note: Requested on January 21, 1999.

Effective Date: Ninety days after adjournment of session in which bill is passed.

Testimony For: Computerization allows for the fast exchange of large amounts of data and genetic information is personal and needs to be protected from misuse. Genetic tests are useful, but individuals are not having them performed because of the fear that the information will be used against them by insurance companies.

Testimony Against: Banning the use of genetic information will inhibit the treatment of patients with genetic diseases. This bill is not necessary in a guarantee issue state such as Washington. The state cannot regulate the self-insured market; therefore, this bill would fail to cover many citizens.

Testified: Senator Franklin (sponsor); Philip L. Bereano, Washington Biotechnology Action Council (pro); John Moore, Individual (pro); Deana Knutsen, Washington Citizen Action (pro); Kris Coppin, Individual (pro); Ken Bertrand, Group Health Cooperative (con); David Allen, American Cancer Society (pro).