

SENATE BILL REPORT

SSB 5284

As Passed Senate, March 12, 2001

Title: An act relating to informed consent in the use of DNA.

Brief Description: Requiring informed consent before a person's DNA is used for genetic testing.

Sponsors: Senate Committee on Human Services & Corrections (originally sponsored by Senators Franklin, Winsley and Kohl-Welles).

Brief History:

Committee Activity: Human Services & Corrections: 1/31/01, 2/22/01 [DPS].
Passed Senate: 3/12/01, 46-0.

SENATE COMMITTEE ON HUMAN SERVICES & CORRECTIONS

Majority Report: That Substitute Senate Bill No. 5284 be substituted therefor, and the substitute bill do pass.

Signed by Senators Hargrove, Chair; Costa, Vice Chair; Carlson, Franklin, Hewitt, Kastama, Kohl-Welles, Long and Stevens.

Staff: Edith Rice (786-7444)

Background: DNA means deoxyribonucleic acid, a component of human body cells. Analysis of DNA produces a sequence of chemical base pairs (A = adenylic acid, T = thymidylic acid, C = cytidylic acid, and G = guanylic acid), which is unique to the individual.

Researchers, scientists, criminal experts, and businesses value interpretation of the unique sequences. The federal government is competing with private researchers to map the entire human genome. The preliminary mapping work is essentially completed. The federally supported effort is called the Human Genome Project; a segment of that project operates out of the University of Washington.

In the 1999 session, the Legislature enacted House Concurrent Resolution 4412, which resulted in an interim committee on DNA Identification. The resolution directed House and Senate members to study the policy implications relative to scientific advances that are making DNA useful. The resolution required consideration of privacy concerns given the wealth of individual information available from DNA. The committee did not make any consensus recommendations, but several bills were introduced in the 2000 session. The language in this bill passed the Senate, but not the House.

Current law does not have a requirement that informed consent be obtained when a person's individually identifiable DNA is obtained for purposes of genetic testing. Health care providers are required to obtain informed consent for health care treatment, and must have

consent to communicate health care information. Genetic testing is performed for purposes other than medical treatment, and may be used by a health care provider for purposes other than your health care.

Summary of Bill: Informed consent is required when an individual's identifiable DNA is obtained for genetic testing purposes.

A person must be informed of a number of different items listed.

Exceptions exist to the informed consent requirement for criminal matters, paternity or child support cases, emergency medical care, research conducted under the regulation of an institutional review board, health care providers operating under state or federal privacy laws, and pursuant to a specific authorizing statute. Deceased persons cannot consent; therefore, a court of law or institutional review board weighs the privacy concerns and determines whether testing could occur.

Appropriation: None.

Fiscal Note: Not requested.

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

Testimony For: DNA is the last opportunity to protect individual privacy. A person has the right to know when DNA is being used.

Testimony Against: Federal law addresses these concerns. State law variations on informed consent create a barrier to research and researchers have to spend time and money complying with varying provisions. Quick and ready access to this information is needed. Informed consent is not always possible. The language is not clear.

Testified: Senator Franklin, sponsor (pro); CON: Linda Hull, Washington Biotechnical and Biomedical Association; Mike Ryherd, Fred Hutchinson Cancer Research Center; David Stillman, DSHS/Division of Child Support; Ken Bertrand, Group Health.