
**Financial Institutions &
Insurance Committee**

HB 2772

Brief Description: Controlling genetic information.

Sponsors: Representatives Schual-Berke, Cody, O'Brien, Simpson, G., Moeller, Dickerson, Chase and Conway.

Brief Summary of Bill

- Defines "genetic information."
- Defines "informed consent" and requires informed consent prior to obtaining, using, storing, or disclosing a person's genetic information, with noted exceptions.
- Prevents discrimination in employment and life insurance transactions based on genetic information.

Hearing Date: 2/3/04

Staff: Carrie Tellefson (786-7127).

Background:

Genetics:

DNA means deoxyribonucleic acid, a nucleic acid that constitutes the genetic material of all cellular organisms and the DNA viruses; DNA replicates and controls through messenger RNA the inheritable characteristics of all organisms. A molecule of DNA is made up of two parallel twisted chains of alternating units of phosphoric acid and deoxyribose, linked by crosspieces of the purine bases and the pyrimidine bases, resulting in a right-handed helical structure, that carries genetic information encoded in the sequence of the basis. Researchers, scientists, criminal experts, and businesses value interpretation of the unique sequences.

Recent advances in genetics research are the work of thousands of scientists in dozens of countries; however, the most significant discovery was announced in April 2003 when a team of scientists determined the exact sequence of the human genetic code and placed that information in public databases. The most immediate use of the data from sequencing the genome will be to increase the understanding of the link between genes and disease. Medicine has already benefitted from the first of what will eventually become many new discoveries about the links between genetic mutations and particular diseases. One example of such a link is the correlation between

mutations in two genes - BRCA1 and BRCA2 and an elevated risk of breast and ovarian cancer. If used to guide medical decision-making, a test for a mutation in one of the two BRCA genes could benefit women in evaluating their risk of disease and in taking steps to reduce the risk.

Use of Genetic Information in Employment:

Although genes are neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Members of those groups may be stigmatized or discriminated against as a result of that genetic information. This became evident in the 1970s with the introduction of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. The screening programs were designed to identify both healthy carriers and carriers with the disease, even though neither prenatal diagnosis nor treatment was available. Scientists suggested that even healthy carriers might be hyper-susceptible to certain work place toxins, such as benzene, lead, cadmium, carbon monoxide, and cyanide. Based on these opinions, employers began testing workers for the gene even though available evidence and studies did not support this theory.

Title VII of the Civil Rights Act of 1964 makes it illegal for an employer, labor organization, employment agency, or training program to discriminate against any individual because of the individual's race, color, religion, sex, or national origin. Chapter 49.60 RCW provides that individuals have the right to be free from discrimination because of race, creed, color, national origin, sex, or the presence of any sensory, mental, or physical disability or the use of a trained dog guide or service animal by a disabled person.

Use of Genetic Information in Insurance:

Life insurance companies can use health care information, including genetic information, to deny coverage or to set initial premiums. There are no laws preventing the use of preexisting conditions in life insurance underwriting. However, regulations do prohibit cancellation of a policy because of health conditions that emerge after issuance. Life insurance rates are term-based and policies may be periodically re-classified. Individual, small-group, and large-group health insurance plans may contain a waiting period of up to nine months for coverage of preexisting conditions, but genetic information cannot be considered a health condition unless it is accompanied by a diagnosis of the condition. Preexisting condition limitations vary for long-term care, Medicare supplemental, individual or group disability insurance. The use of genetic information to define a preexisting condition may not be prohibited by law for some long-term care, Medicare supplemental, individual, or group disability insurance plans.

The American Academy of Actuaries notes that private insurers do not require applicants for insurance to undergo genetic testing or use genetic tests to limit coverage for preexisting conditions. Another study reported in the American Journal of Human Genetics, reports that in a study of insurance practices, there are almost no well-documented cases of health insurers either asking for or using presymptomatic genetic test results in their underwriting decisions. The same study found that "some insurers clearly do use family history information for important disease categories such as heart disease, cancer, and diabetes, but they do so only to look for or evaluate other signs of existing or prior disease, not to predict the onset of future health problems."

Disclosure of Genetic Information and Informed Consent:

Both federal and state law require health care providers to obtain informed consent prior to disclosing health care information. State laws on this topic include the Uniform Health Care

Information Act, the Patient's Bill of Rights, Release of Records for Research, and various other laws and rules that regulate the privacy of health care information held by health care providers, health insurers and hospitals. In 2002, the Legislature amended the definition of "health care information" in the Uniform Health Care Information Act to include DNA. The federal Health Insurance Portability and Accountability Act (HIPAA) privacy rules prohibit "covered entities," such as health care providers, payors, and health care clearinghouses from disclosing medical information without consent. However, medical information may be distributed beyond these "covered entities." HIPAA privacy rules do not directly affect employers or other non-covered entities. However, if a "covered entity" shares information with a "non-covered entity," the non-covered entity becomes a "business associate" under HIPAA and must enter into an agreement with the covered entity ensuring that it will protect the privacy of the information that is shared between them.

Summary of Bill:

Genetic information is defined as information about inherited characteristics that is derived from a DNA-based or other laboratory test, family history, or medical examination.

Informed Consent:

An individual's genetic information is their property and may not be obtained, used, stored, or disclosed for any purpose without first obtaining the individual's written informed consent. Informed consent requires an explanation of the use of the information; identification of the entity obtaining it; disclosure that the information will be shared and with whom; the duration that genetic information may be kept; reasonably foreseeable risks or harm associated with providing the genetic information; how the genetic information will be maintained and whether the sample will be destroyed or stored, including how and where it will be stored; reasonably expected benefits or advantages relating to providing the genetic information; confidentiality or privacy protections; identification of an individual contact for purposes of receiving future information related to the genetic information; information regarding whether genetic information may be expunged or removed and the method for doing so; the exclusion of any exculpatory provisions from liability; and a disclosure that providing genetic information is voluntary.

Informed consent must be granted in writing each time genetic information is obtained, used, stored, or disclosed. However, an individual may authorize continuous informed consent for research purposes.

Informed consent is not required:

- in criminal matters if obtained as part of a criminal investigation, or related adjudication; once a criminal conviction is final, any genetic information identifying a specific individual will be destroyed if the individual was found innocent;
- for emergency medical care, so long as the person is informed as soon as possible that genetic information was obtained;
- when the individual is deceased and the requester establishes in a court of law that obtaining the information benefits public health, safety, and welfare, and outweighs the harm to the individual's privacy interests, or the person requesting the information is a family member requesting the information for health care or other purposes that outweigh the harm to the individual's privacy interests; or the requester has been authorized by an institutional review board to use the genetic information;

- when the requester is a health care provider and is subject to the HIPAA privacy rules
- when the requester is acting according to the provisions of an institutional review board established under federal law;
- in death investigations for identification purposes;
- in paternity proceedings, but information may not be disclosed without informed consent of the person who provided the specimen or a court order;
- when the division of child support has issued an order for genetic testing under state law, but information may not be disclosed without informed consent of the person who provided the specimen or a court order.

Genetic Discrimination in Life Insurance:

A life insurer may not require or use genetic information as a basis for discrimination.

Genetic Discrimination in Employment:

An employer may not require an employee or prospective employee to submit genetic information or submit to screening for genetic information as a condition of employment or continued employment. If an employer has genetic information about an employee when this law is enacted, the employer must not disclose the genetic information without the employee's informed consent.

This law does not repeal or override any other state laws related to discrimination based on genetic information.

It is an unfair practice for an employer, labor union, or employment agency to refuse to hire a person because of genetic information; to discharge or bar a person from employment because of genetic information; to discriminate against a person in compensation or other terms of employment because of genetic information; to induce a person to disclose genetic information; to question a person about his or her genetic information; to require a person to submit to a genetic test as a condition of employment or continued employment; or to collect, solicit, or require disclosure of genetic information as a condition of employment, employment classification, assignment, referral, or a condition of membership in a union.

Appropriation: None.

Fiscal Note: Not requested.

Effective Date: The bill takes effect 90 days after adjournment of session in which bill is passed.