

HOUSE BILL REPORT

ESHB 2772

As Passed House:
February 16, 2004

Title: An act relating to genetic information.

Brief Description: Controlling genetic information.

Sponsors: By House Committee on Financial Institutions & Insurance (originally sponsored by Representatives Schual-Berke, Cody, O'Brien, G. Simpson, Moeller, Dickerson, Chase and Conway).

Brief History:

Committee Activity:

Financial Institutions & Insurance: 2/3/04, 2/6/04 [DPS].

Floor Activity:

Passed House: 2/16/04, 94-0.

Brief Summary of Engrossed Substitute Bill

- Defines "genetic information."
- Defines "genetic test."
- Prevents discrimination in employment and life insurance transactions based on genetic information.

HOUSE COMMITTEE ON FINANCIAL INSTITUTIONS & INSURANCE

Majority Report: The substitute bill be substituted therefor and the substitute bill do pass. Signed by 10 members: Representatives Schual-Berke, Chair; G. Simpson, Vice Chair; Benson, Ranking Minority Member; Newhouse, Assistant Ranking Minority Member; Cairnes, Carrell, Hatfield, Roach, Santos and D. Simpson.

Minority Report: Without recommendation. Signed by 1 member: Representative Cooper.

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." The 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 Engrossed Substitute Bill:

"Genetic information" means written or recorded information about genes, gene products, or genetic characteristics derived from an individual or a family member of the individual. "Gene product" is a scientific term that means messenger RNA and translated protein. "Genetic information" does not include routine physical measurements: Chemical, blood, and urine analysis, unless conducted purposely to diagnose a genetic characteristic; tests for the abuse of drugs; tests for cholesterol; and tests for the presence of HIV. Family histories are not considered genetic information.

"Genetic test" means a test of human DNA, RNA, mitochondrial DNA, chromosomes, or other material for the purpose of identifying genes, inherited or acquired genetic abnormalities, or the presence or absence of inherited or acquired characteristics in the genetic material. "Genetic test" does not include tests given for cholesterol or HIV. Employers may

test for the presence of drugs or alcohol, but may not use the results of these tests to gain genetic information.

Genetic Discrimination in Life Insurance:

Insurers may not require a person to undergo a genetic test or provide the results of a previous genetic test as a condition of offering or renewing insurance. If an insurer has information from a genetic test, the insurer may only use that information if it demonstrates the active presence of disease or illness. An insurer may not use information from a genetic test if the information only demonstrates a propensity for a condition or illness and not the active presence of disease or illness.

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.

Genetic information is included in the list of human "rights." 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.

Testimony For: (In support) This bill is very important to the Jewish community. Many communities have been shown to have a high propensity for a variety of cancer-linked genes in genetic studies. There have been two national cases that involve the improper use of genetic information to discriminate against groups or individuals in employment. They support changing the definition to address the concerns related to medical research. The primary goal here is to prevent misuse of genetic information. Some people think genes will

predetermine a health condition. They have been working on this legislation for years. Washington is one of only a few states that don't have any protections in current law. Forty-six other states have some form of protection regarding genetic information.

NOW supports the bill. It's important to prevent discrimination in employment and in life insurance and to clarify that this comes within the purview of the Human Rights Commission.

The labor council supports the bill. Privacy of genetic information is important. Employers may try to avoid hiring employees because of specific genetic traits. Employers are not prohibited from hiring or not hiring based on genetic information. Insurers can use genetic information in the individual market and can require applicants to take genetic tests. Both former President Clinton and President Bush support a genetics bill that is currently before Congress. It passed the Senate and is on its way to the House.

Breast cancer causes uncertainty in lives. There are genetic predispositions that exist in families. Research is critical to the development of a cure. Don't allow insurance or employment discrimination and don't impeded research.

(In support w/amendment) The ACLU pays close attention to the privacy issues and supports this bill. They would suggest removing the reference to genetic information as "property." Genetic research projects have come under fire recently where informed consent was not thorough enough with respect to the therapies proposed. Genetics and research has also become intertwined with business, venture capitalism, patent rights, and initial public offerings. In Washington, there are deeply disputed matters that are now in litigation regarding whether informed consent was adhered to. They want to keep the informed consent provision. Federal regulations are a floor. It's okay to have state laws with higher standards than the federal laws. This testimony is dedicated to Ernest Hendent, who recently died at the age of 96. He was the last man in the United States who was involved in the Tuskegee syphyllis study.

(Concerns) UW Medicine is concerned about the informed consent provisions. They agree with the biotech industry comments with respect to this bill. They have submitted recommendations regarding changes and are interested in continuing to work on this bill.

Fred Hutchinson also agrees with the biotech industry comments. They receive more funding than anyone else in the country for genetic research. They take a more stringent approach to informed consent, going beyond what federal law requires. They suggest an amendment in the informed consent provision is needed regarding anthropological research - e.g. "Kennewick man." The concept of informed consent has changed drastically with the era of computers and technology. They believe the informed consent section should be removed from the bill.

Medical information must be treated confidentially and must not be misused. The biotech community supports the changes regarding life insurance and employment, but does not support the informed consent provisions. They supported the inclusion of "DNA" in the 2002 legislation. The problem with individual informed consent laws is that this is primarily

regulated at the federal level. It's duplicative to have additional state laws and it adds another level of regulation. They would also like to see a different definition of genetic information.

The life insurers do not currently use genetic test of information. However, they need to be able to estimate a person's lifespan in order to rate it. Different companies accept different risks. They support the informed consent provisions of the bill. They also have worked well with the laws in Oregon. They support prohibition that life insurers can't require genetic information. The term added in the life insurance provision is insured or "prospective insured" which is too broad because that could mean anyone. References to "family history" or "medical examinations" in the definition of genetic information are problematic as well because life insurers look at family history and may require medical examinations as part of their underwriting process. They are willing to continue to discuss alternative language. If insurers in the 46 other states with genetics laws have found a way to write life insurance, this should work here too.

Testimony Against: None.

Persons Testifying: (In support) Representative Schual-Berke, prime sponsor; Remy Trupin, Jewish Foundation of Greater Seattle; Chris Coppin, American Cancer Society; Lonnie Johns Brown, NOW; Randy Loomans, Washington State Labor Council; and Don Sloma, State Board of Health.

(In support w/amendment) Jerry Sheehan, ACLU-Washington.

(Concerns) Vicki Austin, WBBA; Basil Badley, ACLI; Jackie Der, University of Washington Medical; and Mike Ryherd, Fred Hutchinson Cancer Research Center.

Persons Signed In To Testify But Not Testifying: None.