

SUBJECT: Discrimination based upon genetic information

COMMITTEE: Economic Development — favorable, without amendment

VOTE: 8 ayes — Jim Solis, Van de Putte, Deshotel, Homer, Keffer, Luna, McClendon, Seaman

0 nays

1 absent — Yarbrough

SENATE VOTE: On final passage, May 5— voice vote

WITNESSES: For — Jill Aslakson, Texas Medical Association; Mark Rothstein

Against — None

BACKGROUND: The 75th Legislature enacted HB 39 by McCall, prohibiting discrimination based upon genetic information for purposes of employment, health insurance eligibility, and issuance of occupational licenses.

Genetic information is considered confidential, even by subpoena, without written authorization from the individual to whom the information pertains. Samples of genetic material taken for a genetic test must be destroyed promptly after the test unless the individual authorizes retention for specific reasons allowed under law. Entities holding genetic information may disclose it without written authorization under certain explicit circumstances.

DIGEST: SB 538 would revise portions of the Labor Code, Insurance Code, and art. 9031, VTCS, to amend the 1997 law that prohibited discrimination based upon genetic information. The bill would redefine genetic information as information about genes, gene products, or inherited characteristics that may derive from an individual or family member.

The bill would give individuals the right to refuse to know the results of their genetic test, in which case the doctor could not disclose the results to that person.

SB 538 would allow people to authorize retention of samples of their genetic material for the purpose of DNA banking. Retention of a sample would be required if the sample was required by an organization that performed genetic tests and was recognized by the Texas Department of Health.

The bill would add a circumstance under which an entity holding genetic information could disclose that information. The information could be disclosed to the doctor who referred the person for the genetic test.

The bill would take effect September 1, 1999. Amendments to the Insurance Code would apply only to an insurance policy or evidence of coverage delivered, issued for delivery, or renewed on or after January 1, 2000.

**SUPPORTERS
SAY:**

An individual with an abnormal or mutated gene does not have a disease but merely the potential to develop the disease, and discrimination based on this potential is egregious and unfair. SB 538 would clarify and improve the 1997 law regarding discrimination based upon a person's genetic information. The current definition of "genetic information" is too narrow and does not include a person's family history, which could indicate a predisposition to a disease. This bill would close that loophole and ensure that a person's specific genetic information or inherited characteristics would be protected under the law.

The bill also would guarantee a person's right not to know information derived from a genetic test. This right is as important as the right to know such information. Learning certain information, such as a predisposition to a life-threatening disease, could be devastating. SB 538 would ensure that persons being tested could retain control over their lives and could decide what they want to know and when.

**OPPONENTS
SAY:**

SB 538 would broaden the definition of "genetic information" to include almost any information about a person. This would create additional confusion over what would constitute a violation under the law. The definition should remain as it is so that only information derived from a genetic test would be considered "genetic information."

Laws regulating discrimination based upon genetic testing are unnecessary, because such discrimination is not a problem in the workplace. Also, federal laws are in place to prohibit such discrimination. Redundant state laws create confusion and a separate cause of action for employees to sue employers. In

addition, federal law already prohibits insurance companies from using genetic information as a preexisting condition to deny enrollment.

OTHER
OPPONENTS
SAY:

The bill's intent in broadening the definition of "genetic information" is to protect additional information about a person's medical records. However, the revised definition in the Insurance Code would differ from that in the Labor Code and the civil statutes in that the Insurance Code definition would include genes, gene products, or inherited characteristics *derived from the results of a genetic test*. This would leave a loophole for information gained from family history, which insurance companies could use to discriminate against an untested person. This also would create inconsistent definitions for the same term in different statutes that concern discrimination based upon genetic information.