

**SUBJECT:** Prohibiting discrimination based upon genetic information

**COMMITTEE:** Economic Development — committee substitute recommended

**VOTE:** 8 ayes — Oliveira, Yarbrough, Greenberg, Keffer, Luna, Raymond, Seaman, Van de Putte

0 nays

1 absent — Siebert

**WITNESSES:** (Before subcommittee and full committee)

For — Cindy Antolik, American Cancer Society; Laura Saponara, American Civil Liberties Union; Judith Sokolow, Advocacy Inc.; Martin Zindenberg, Texas Healthcare and Bioscience Institute; Michael Polland, Texas Life Insurance Association

Against — Christopher A. Knepp, Texas Employment Law Council; Charles M. Taylor, Texas Association of Business and Chambers of Commerce; Jay A. Thompson, Texas Life Insurance Association

On — Gordon Mills, UT M.D. Andersen Cancer Center; Diane Moellenberg, Texas Department of Insurance; Will D. Davis, Texas Life Insurance Association

**DIGEST:** CSHB 39 would prohibit discrimination based upon genetic information for employment, health insurance eligibility, and issuance of occupational licenses.

Genetic information would be defined as information derived from the results of a genetic test and a genetic test as a laboratory test of DNA, RNA, or chromosomes to identify genetic mutations or alterations associated with a predisposition for a disease. Genetic testing would not include a routine test performed as part of a physical exam, a test to determine drug use or the presence of HIV, or a chemical, blood or urine analysis.

### **Employment**

CSHB 39 would add the use of genetic information to antidiscrimination provisions in the Labor Code. It would prohibit an employer, labor organization or employment agency from refusing to hire or refer an individual for employment or to fire or otherwise discriminate against an individual on the basis of genetic information or refusal to take a genetic test. It would also make it unlawful to limit, segregate or classify an employee in a way that would deprive or tend to deprive employment opportunities because of genetic information or refusal to take a genetic test.

### **Occupational and professional licenses**

CSHB 39 would prohibit denying, revoking, suspending, or refusing to renew an occupational or professional license based upon refusal to submit to a genetic test, refusal to reveal if an individual has taken a genetic test, or refusal to reveal results of a genetic test. The prohibition would apply to all state agencies and political subdivisions that issue licenses.

### **Group health insurance plans**

CSHB 39 would prohibit the use of genetic information by a group health benefit plan to reject, deny, limit, cancel, refuse to renew, increase premiums for or otherwise adversely determine eligibility for coverage.

CSHB 39 would define group health benefit plan as a plan that contracts directly for health care services on a risk-sharing basis, including plans providing benefits for medical or surgical expenses incurred as a result of a health condition, accident or sickness. The definition would not include plans covering specific diseases or accidental death or dismemberment or small employer or long-term care plans.

A plan issuer could request a genetic test for nondiscriminatory purposes but would first have to notify the applicant the test was required, disclose the proposed use of the test results, and obtain the applicant's written consent prior to administering the test. In addition, the plan issuer would have to ensure that the applicant received an interpretation of the test results by a qualified health care practitioner and that a physician designated by the applicant received a copy of the test results.

CSHB 39 would prohibit group health benefits plans from disclosing genetic information to others in most circumstances. It would allow redisclosure for actuarial or research studies if the tested individual was not identified in the report and any identifying materials were returned or destroyed. A group health benefit plan also would be able to disclose genetic information to the Texas Department of Insurance for the purposes of enforcing the statute and for purposes directly related to business decisions on the purchase, transfer or sale of part of an insurance business.

CSHB 39 would allow the Texas Department of Insurance to issue a cease and desist order to compel compliance with the antidiscrimination and confidentiality provisions. If the violator failed to comply with the cease and desist order, the department would be able to revoke or suspend the issuer's authority to engage in operating a group health benefit plan.

**Other provisions**

The bill would make genetic information confidential, private and privileged information. Entities covered by the bill could not disclose genetic information, even by subpoena, without written authorization from the individual to whom the genetic information pertained. The prohibition against disclosure also would apply to any secondary recipient of the information.

Individuals or their legal representatives could allow disclosure of genetic information via written authorization that described the information being disclosed, the name of the person involved, and the purpose of the disclosure.

Entities holding genetic information could disclose genetic information without written authorization under certain explicit circumstances: when authorized by state or federal criminal law to identify individuals or in a criminal or juvenile proceeding, inquest, or child fatality review; if required by a court; or if authorized to establish paternity. Genetic information also could be disclosed without specific authorization from the individual in order to identify decedents or to furnish information to a decedent's blood relatives for medical diagnostic purposes or for research purposes, if the individual's name was not used in connection with the information.

CSHB 39 would require that genetic material used in genetic testing be destroyed, with a few exceptions. The sample could be retained by court order; if the individual tested authorized the retention for medical treatment or scientific research; for research purposes governed by an institutional review board; or if the sample was obtained from a newborn child for the purposes of screening for hereditary diseases.

CSHB 39 also would guarantee an individual's right to know results of all genetic tests.

CSHB 39 would take effect September 1, 1997. Its provisions would apply to occupational licenses issued or renewed on or after that date and to group health benefit plans issued or renewed on or after January 1, 1998.

**SUPPORTERS  
SAY:**

CSHB 39 would ensure that a promising new scientific technology was used to the benefit of Texans rather than to their detriment. The bill would protect the privacy of genetic information by making it unlawful for employers, insurance companies, and other entities to use genetic information to discriminate against individuals.

Currently, genetic testing in Texas is confined primarily to criminal proceedings and identifying deceased individuals. However, genetic testing is increasingly being used for medical diagnoses and to determine if an individual is genetically predisposed to a certain disease. Scientists have developed genetic tests for 100 different diseases, including thyroid cancer, sickle-cell anemia, diabetes, Tay Sachs disease, breast cancer, and leukemia.

However, individuals with a history of disease in their families may resist undergoing genetic testing because they are afraid their health insurance company will use information from the tests to deny health coverage.

Researchers and doctors predict that in the next three to five years, genetic testing will be inexpensive and accessible. Under CSHB 39, individuals would not be afraid to undergo genetic testing and based upon the results, would be able to take preventative measures to safeguard against the disease. For example, individuals who test positive for the genes found to cause breast cancer will know to go in for annual mammograms and do frequent self-examinations. Unless she knows she is predisposed to breast cancer, a

woman might not start annual mammograms until she is 40 — and that might be too late to catch the disease in time for early treatment.

An individual with an abnormal or mutated gene does not have a disease but merely the potential to develop the disease. Allowing discrimination based on this potential would be egregious and unfair. CSHB 39 would amend Texas law by adding safeguards on two levels, preventing both unauthorized review of genetic information and illegal use of the information to deny health coverage or employment opportunities.

CSHB 39 would empower individuals by guaranteeing them control over their personal genetic information. Genetic information is private information that should only be used with the express permission of the individual. CSHB 39 would respect an individual's right to privacy by prohibiting abuse of genetic information by insurance companies and employers.

CSHB 39 also would prevent the creation of an uninsurable contingent of Texans. If insurance companies were allowed to use genetic information as a basis for denying health coverage, it is possible that only individuals without genetic mutations would be insured. CSHB 39 is necessary to protect these individuals and their families.

CSHB 39 would punish abusers of genetic information. Employers that fired workers because of their genetic makeup could be sued. This separate cause of action would be a proper remedy for discrimination that violated not only the affected individual's right to privacy but also, because genetic information may be inherited, all the relatives of that person. Employers and insurance companies that abuse genetic information should be punished for their discriminatory practices.

CSHB 39 is consistent with other antidiscrimination statutes that protect individuals from discrimination based upon race, sex and national origin. In addition, CSHB 39 would help clarify the application to genetic testing of the federal Americans with Disabilities Act, which outlaws discrimination based in part on the perception of a disability. The potential for developing an illness that could be discovered through genetic testing should qualify as a perception of disability under the ADA. Since this interpretation of the

ADA has not yet been tested in the courts, it is important that Texas enact its own law to provide explicit protection against this type of discrimination.

Although it is unlawful in Texas for unlicensed companies to sell group health insurance, CSHB 39 would apply to all companies, regardless of their licensing status. Health insurance plans should not be able to abuse genetic information, regardless of their regulatory status.

CSHB 39 would not harm the insurance business. In fact, it could potentially save insurance companies money in the long run. If individuals knew they were predisposed to cancer based upon a genetic test, they would be able to seek out preventative measures that would be less expensive than treating a developed cancer. Furthermore, CSHB 39 would apply only to group health insurance plans that pool risk to underwrite group policies. It would not apply to all insurance companies because risk is not divided in the same way on individual policies.

Because CSHB 39 would protect the privacy of genetic information, more people would seek out genetic testing. The more genetic testing done, the more doctors and researchers will know about these diseases, and the more likely they will be able to find effective treatments and cures.

The bill would stipulate that insurance companies requiring a genetic test for nondiscriminatory purposes provide a qualified practitioner to interpret the results of the test to a participating individual. If a company requires the test, it is only fair that it also ensure proper interpretation of its results.

Although to date there have been few, if any, cases of discrimination based upon genetic information, it is important that public policy keep ahead of technology in this field. Genetic testing will be very accessible in the near future, so it is important to enact this legislation now.

**OPPONENTS  
SAY:**

CSHB 39 is premature because discrimination on the basis of genetic information is not a problem in the workplace. The federal ADA already protects individuals against discrimination based upon genetic information because of the protections afforded persons perceived to have disabilities.

CSHB 39 would not only be redundant but also would create a separate cause of action for employees to sue employers for something employers already are not allowed to do. In addition, the Health Insurance Portability and Accountability (Kassebaum-Kennedy) Act, enacted by Congress in 1996, prohibits a group health insurance plan from using genetic information as a pre-existing condition to deny enrollment.

CSHB 39 would interfere with the free flow of information on which the health insurance industry is based. Prohibiting the use of genetic information would adversely affect business decisions on underwriting insurance policies because it would skew the use of risk as a factor in these decisions.

Furthermore, CSHB 39 would place an unnecessary burden on health insurance companies by requiring that they have a qualified health practitioner provide individuals with an interpretation of genetic test results.

OTHER  
OPPONENTS  
SAY:

CSHB 39 would wrongly exclude small employer plans and other individual health plans from its protections. Every Texan with health insurance should be protected against discrimination based upon genetic information, regardless of their type of health plan. CSHB 39 should be amended to apply to all health insurance plans.

In addition, the definition of genetic testing is too narrow. Often, doctors and researchers look at genes by looking at their proteins. By not including the analysis of proteins in the definition of genetic testing, CSHB 39 would create a loophole for insurance companies and employers to discriminate. The definition of genetic information also is incomplete because it does not include information gained from family history, which insurance companies could use to discriminate against an untested individual. The definition of genetic testing should be expanded to include protein analysis and the definition of genetic information amended to cover family medical histories.

CSHB 39 would require the Texas Department of Insurance to regulate health insurance plans that it does not license. These plans are regulated by federal laws; reference to them in the bill is confusing and unnecessary.

NOTES: Rep. McCall plans to offer a floor amendment to include protein analysis within the definition of genetic testing.

The committee substitute changed the original bill to:

- delete the definition of genetic characteristic;
- change the definition of genetic information to only include information derived from a genetic test;
- change the definition of genetic test to include analysis of DNA, RNA and chromosomes and exclude tests for a routine physical, tests to determine drug use or HIV or chemical, blood, or urine analyses;
- allow disclosure of genetic information for research purposes if the individual was not identified;
- guarantee tested individuals the right to know their test results;
- allow for retaining genetic samples for use in medical treatment or for scientific purposes or if they were obtained for research purposes cleared by an institutional review board or during a screening test for newborns;
- apply only to group health benefit plans;
- add circumstances when health insurance plans could authorize disclosure of genetic information;
- add administrative penalties for violation; and
- authorize a cease and desist order.

A similar bill, CSSB 98 by Zaffirini et al., was reported favorably by the Senate Economic Development Committee on March 24. CSHB 263 by Van de Putte, which would prohibit individual and group health insurance providers from discriminating on the basis of genetic information, was reported favorably by the House Insurance Committee on March 3. A related measure, HJR 66 by Solomons, which proposes a constitutional amendment to establish the right to privacy of a person's genetic information, is scheduled for a public hearing today by the House State Affairs Committee.

During the 74th legislative session, a similar bill, HB 343 by Van de Putte, was left pending in the Economic Development Committee.