BILL ANALYSIS

Senate Research Center 87R21793 JG-D C.S.S.B. 962 By: Hughes Health & Human Services 5/6/2021 Committee Report (Substituted)

AUTHOR'S / SPONSOR'S STATEMENT OF INTENT

Genetic testing and analysis is immensely popular today, and while some companies give a very thorough explanation of their use of a participant's DNA (deoxyribonucleic acid), not all do. Furthermore, there is a lot of ambiguity around the necessary mass testing for COVID-19 regarding how long testing samples are kept and what they are used for. S.B. 962 seeks to give Texans greater protection and transparency when it comes to collection of their DNA.

Specifically, S.B. 962 requires that any person collecting genetic material or genetic information, performing genetic analysis of an individual, retaining an individual's genetic material or genetic information, or disclosing, including through sale or donation, the individual's genetic material or genetic information, for any use, receive informed consent from an individual before doing so.

In this bill, informed consent includes the signing of a consent form that includes the proposed use of DNA, describes an individual's rights under the chapter, and describes the genetic analysis, genetic collection, or other use for which the individual's genetic material or genetic information is obtained. Also, following completion of permitted use the DNA must be destroyed or returned to the individual.

Violation of this chapter is considered a Class A misdemeanor punishable by a fine of up to \$4,000 for the first violation and up to \$10,000 for each subsequent violation. S.B. 962 also provides injunctive relief and authorizes a private right of action. S.B. 962 does not apply to DNA collected as necessary for authorized law enforcement purposes, compliance with a court or administrative order, to identify a deceased individual, as well as several other situations in which law is already established on this subject.

C.S.S.B. 962 clarifies the data covered by the bill, allows for express consent instead of just written consent, includes a few more exemptions, and makes additional changes to better align the bill with HIPPA policy.

C.S.S.B. 962 amends current law law relating to restrictions on the use and disclosure of certain genetic material and genetic information, provides a civil penalty, and creates a criminal offense.

RULEMAKING AUTHORITY

This bill does not expressly grant any additional rulemaking authority to a state officer, institution, or agency.

SECTION BY SECTION ANALYSIS

SECTION 1. Amends Subtitle H, Title 2, Health and Safety Code, by adding Chapter 174, as follows:

CHAPTER 174. RESTRICTIONS ON USE AND DISCLOSURE OF CERTAIN GENETIC MATERIAL AND GENETIC INFORMATION

Sec. 174.001. DEFINITIONS. Defines "authorized representative," "DNA," "genetic analysis," "genetic characteristic," genetic information," and "genetic material."

Sec. 174.002. USE AND DISCLOSURE OF GENETIC MATERIAL OR GENETIC INFORMATION PROHIBITED; EXCEPTIONS. (a) Prohibits a person, subject to other law other than Subsection (c) and unless an individual or the individual's authorized representative provides express consent, from:

(1) obtaining the individual's genetic material or genetic information;

(2) performing a genetic analysis of the individual or any other analysis or test of the individual that requires the individual's genetic material;

(3) retaining the individual's genetic material or genetic information; or

(4) disclosing, including through sale or donation, the individual's genetic material or genetic information.

(b) Provides that, for purposes of Subsection (a), an individual or the individual's authorized representative provides express consent if, after receiving a written disclosure statement that clearly and prominently describes the manner in which the individual's genetic material or genetic information or the results of a genetic analysis or other analysis or test of the individual will be collected, used, retained, maintained, or disclosed, the individual or representative takes an affirmative action demonstrating an intentional decision to provide consent. Requires that the disclosure statement at a minimum:

(1) disclose the proposed use of the individual's genetic material or genetic information;

(2) describe the individual's rights regarding the collection, use, retention, maintenance, or disclosure of the individual's genetic material or genetic information or the results of a genetic analysis or other analysis or test of the individual;

(3) describe the genetic analysis, genetic collection, or other use for which the individual's genetic material or genetic information is obtained; and

(4) describe the nature of the resulting genetic material or genetic information, including a DNA profile, obtained from the genetic analysis, genetic collection, or other use of genetic material.

(c) Provides that the prohibitions under Subsection (a) do not apply to an individual's genetic material or genetic information that is:

(1) disclosed to the individual or the individual's authorized representative;

(2) obtained for use by a clinical laboratory from the individual's treating physician in the diagnosis or treatment of the individual;

(3) disclosed as part of an authorized research project under which the identity and genetic material of the individual is de-identified in accordance with the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. Section 1320d et seq.);

(4) obtained or otherwise necessary for use:

(A) for an authorized law enforcement purpose;

(B) to comply with a court order;

(C) under an administrative order to determine the paternity of an individual or for another purpose;

(D) to identify a deceased individual;

(E) to conduct a newborn screening test under Chapter 33 (Phenylketonuria, Other Heritable Diseases, Hypothyroidism, and Certain Other Disorders);

(F) to provide emergency medical services;

(G) under a third-party service contract or other obligation for the storage, retrieval, handling, or transmission of the DNA or DNA record; or

(H) to comply with federal law; or

(5) made public by the individual.

(d) Provides that Subsection (c)(2) does not waive any requirement for a physician to obtain informed consent from an individual before extracting genetic material from the individual for the performance of a genetic analysis or for another purpose.

(e) Provides that the use of an individual's genetic material or genetic information permitted under Subsection (c) is restricted to only that permitted use and the material or information, subject to Subsection (f), is required to be destroyed or returned to the individual or the individual's authorized representative immediately on completion of the permitted use.

(f) Requires a person who obtains an individual's genetic material to perform a genetic analysis of the individual for a permitted use under Subsection (c), immediately on completion of the genetic analysis, to destroy the material and any genetic information obtained from the analysis unless the retention of the material or information is:

(1) necessary for a permitted use under Subsection (c); or

(2) specifically authorized by the individual or the individual's authorized representative.

(g) Authorizes an individual or the individual's authorized representative, subject to other law, to inspect, correct, or obtain the individual's genetic material or genetic information.

Sec. 174.003. CRIMINAL PENALTY. (a) Provides that a person commits an offense if the person violates this chapter.

(b) Provides that an offense under this section is a Class A misdemeanor punishable by:

(1) for a first violation of this chapter, a fine of not less than \$3,000 and not more than \$4,000; and

(2) for a second and each subsequent violation of this chapter, a fine of not less than \$4,000 and not more than \$10,000.

(c) Provides that each day a violation occurs or continues to occur is a separate violation for purposes of assessing a penalty under this section.

Sec. 174.004. INJUNCTIVE RELIEF; CIVIL PENALTY. (a) Authorizes the attorney general to bring an action against a person who appears to be in violation of this chapter or is threatening to violate this chapter.

(b) Authorizes a court, in an injunction issued under this section, to include reasonable requirements to prevent any further violations of this chapter.

(c) Authorizes the attorney general, in addition to the injunctive relief provided by Subsection (a), to institute an action for civil penalties against a person for a violation of this chapter. Prohibits a civil penalty assessed under this section from being less than \$4,000 or more than \$10,000 for each violation. Provides that each day a violation occurs or continues to occur is a separate violation for purposes of assessing a penalty under this subsection.

(d) Authorizes the attorney general to recover reasonable expenses incurred in bringing an action under this section, including court costs, attorney's fees, investigative costs, witness fees, and deposition expenses.

(e) Requires the attorney general to file an action under this section in Travis County or in the county in which the violation occurred.

(f) Requires that a civil penalty recovered in an action by the attorney general under this section be deposited in the general revenue fund.

Sec. 174.005. PRIVATE RIGHT OF ACTION. (a) Authorizes an individual whose genetic material or genetic information is obtained, used, or disclosed in violation of this chapter to bring an action to enjoin or restrain a person from committing any further violations of this chapter and to seek damages in the action.

(b) Authorizes a court to award a prevailing party in an action brought under this section reasonable attorney's fees and costs reasonably incurred with the action.

Sec. 174.006. WAIVER OF SOVEREIGN OR GOVERNMENTAL IMMUNITY. Provides that sovereign or governmental immunity, as applicable, of a governmental entity to suit and from liability is waived to the extent of liability created by this chapter.

SECTION 2. Makes application of Chapter 174, Health and Safety Code, as added by this Act, prospective.

SECTION 3. Effective date: September 1, 2021.