

HOUSE OF REPRESENTATIVES STAFF FINAL BILL ANALYSIS

BILL #: CS/HB 833 Unlawful Use of DNA
SPONSOR(S): Judiciary Committee, Tomkow and others
TIED BILLS: IDEN./SIM. **BILLS:** CS/SB 1140

FINAL HOUSE FLOOR ACTION: 85 Y's 28 N's **GOVERNOR'S ACTION:** Approved

SUMMARY ANALYSIS

CS/HB 833 passed the house on April 1, 2021, as amended. The bill was amended in the Senate on April 29, 2021, and was returned to the House. The House concurred in the Senate amendment and subsequently passed the bill as amended on April 29, 2021.

Deoxyribonucleic acid (DNA) is hereditary material existing in the cells of all living organisms. A person's DNA may be collected from his or her biological material and may be used for many purposes, such as criminal investigations, determining paternity, tracking ancestry, or genetic testing to diagnose a medical condition. Since the advent of genetic testing, there have been concerns about third party use of personal genetic information. The current widespread availability of direct to consumer genetic tests has given rise to even more concerns regarding the appropriate use of genetic information. While an individual may voluntarily submit to genetic testing in an effort to gain insights into his or her own genetic history, a third party may seek such information for other purposes. Although existing federal and state laws may protect a person's DNA from being misused by insurance providers or for discriminatory purposes, no current law specifically protects a person's DNA from being collected or analyzed without his or her consent.

The bill creates the "Protecting DNA Privacy Act." The bill creates new crimes prohibiting a person from willfully, and without express consent:

- Collecting or retaining another person's DNA sample with intent to analyze such sample, as a first degree misdemeanor.
- Submitting another person's DNA sample for analysis or conducting or procuring the conducting of such analysis, as a third degree felony.
- Disclosing another person's DNA analysis results to a third party, unless such results were previously voluntarily disclosed by the person whose DNA was analyzed, as a third degree felony.
- Selling or otherwise transferring another person's DNA sample or analysis results to a third party, as a second degree felony.

Under the bill, express consent means authorization from a person or his or her legal guardian or representative, evidenced by an affirmative act demonstrating an intentional decision, after receiving a clear and prominent disclosure regarding the specified purpose for the collection, use, retention, maintenance, or disclosure of the DNA sample or analysis thereof. The bill clarifies current law by providing that "exclusive property" means a person's right to exercise control over his or her DNA sample or analysis with regard to the collection, use, retention, maintenance, disclosure, or destruction of such sample or analysis.

The bill defines the terms "DNA analysis" and "DNA sample" and authorizes a separate criminal penalty for each instance of unlawful collection or retention, submission or analysis, disclosure, or sale of a person's DNA sample or analysis results. The bill applies only to the use, retention, maintenance and disclosure of a DNA sample collected from a person in Florida after the bill is effective and does not apply to a DNA sample, analysis, or analysis results when used for specified purposes such as criminal investigation, determining paternity, complying with a court order, conducting specified research, or other healthcare purposes.

The bill may have an indeterminate positive impact on the number of prison beds by creating new felony crimes relating to unlawful use of DNA.

The bill was approved by the Governor on June 29, 2021, ch. 2021-216, L.O.F., and will become effective on October 1, 2021.

I. SUBSTANTIVE INFORMATION

A. EFFECT OF CHANGES:

Background

DNA

Deoxyribonucleic acid (DNA) is hereditary material that exists in the cells of all living organisms. A DNA profile is created by testing the DNA in a person's cells.¹ Similar to fingerprints, a person's DNA profile is a unique identifier, except for identical twins, who have the exact same DNA profile. A DNA sample may be collected from any biological material, such as hair, teeth, bones, skin cells, blood, semen, saliva, urine, feces, and other bodily substances.² A DNA sample may be used for many purposes, such as:

- Criminal investigations;
- Determining a child's paternity;
- Tracking a person's ancestry;
- Developing vaccines, human growth hormones, or insulin; or
- Genetic testing to diagnose a medical condition or determine predisposition to a particular medical condition.³

Genetic Testing

Since the advent of genetic testing, there have been concerns about the use of personal genetic information by third parties. The availability and use of genetic tests has increased dramatically in recent years. As of August 2017, there were approximately 75,000 genetic testing products on the market, with an average of 10 new testing products entering the market every day.⁴ Genetic testing is generally performed by a healthcare provider who can determine the type of test needed, order the test from a laboratory, collect and send a person's DNA sample, interpret the test results, and then share the results with the patient.⁵ Before a person completes genetic testing from a healthcare provider, a medical professional obtains specified permission to complete the testing, called informed consent. "Informed" means that he or she has enough information to make an educated decision about the testing and "consent" means the person's voluntary agreement to have the testing done.⁶

Direct-to-Consumer Genetic Testing

In recent years, direct-to-consumer (DTC) genetic testing options have become widely available online and in stores. For a relatively low fee, anyone can purchase a DTC genetic test kit allowing a person to spit into a tube or swab the inside of his or her mouth to obtain DNA, mail the sample off, and receive an analysis shortly thereafter. According to an October 2020 Consumer Reports survey, about one in five Americans has taken a DTC genetic test.⁷ Some of the most common brands, such as 23andMe and Ancestry, offer a variety of information, including matching a person with unknown relatives, determining what country a person's ancestors are from, revealing a person's risk of having certain illnesses, and even suggesting what diet is best. However, in addition to potentially useful insights, the

¹ FindLaw, *How DNA Evidence Works*, <https://criminal.findlaw.com/criminal-procedure/how-dna-evidence-works.html> (last visited May 5, 2021).

² *Id.*

³ Revolutionary Science, *Common Uses for DNA Extraction*, (Jul. 9, 2020) <https://www.revsoci.com/common-uses-for-dna-extraction/> (last visited May 5, 2021).

⁴ NCBI, *Genetic Testing and Spending: Where are we Now? Where are we Going?* (May 2018) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5987210/#:~:text=As%20of%20August%2017,tests%20were%20single%20Dgene%20tests> (last visited May 5, 2021).

⁵ MedlinePlus, *What is Direct-to-Consumer Testing?* NIH National Library of Medicine <https://medlineplus.gov/genetics/understanding/dtcgeneticstesting/directtoconsumer/> (last visited May 5, 2021).

⁶ MedlinePlus, *What is Informed Consent*, NIH National Library of Medicine <https://medlineplus.gov/genetics/understanding/testing/informedconsent/> (last visited May 5, 2021).

⁷ Catherine Roberts, *Read This Before You Buy a Genetic Testing Kit*, Consumer Reports, (Feb. 2, 2021) <https://www.consumerreports.org/genetic-testing/genetic-testing-kit-read-this-before-you-buy/> (last visited May 5, 2021).

tests can reveal information a person may prefer not to know, and once a person's genetic data is shared, it can potentially be sold or used to discriminate against him or her.⁸

While DTC genetic testing is increasing the number of people who are able to access their genetic information without involving a healthcare provider or health insurance, regulation of the companies offering such services has not developed accordingly. The U.S. Food and Drug Administration (FDA) reviews some DTC genetic tests, but in general, the FDA does not review tests intended for non-medical, general wellness, or low risk medical purposes or to help a person explore his or her ancestry.⁹

Privacy Concerns

The current widespread availability of DTC genetic tests has given rise to questions and concerns regarding the appropriate use of genetic information. An individual may voluntarily submit to genetic testing in an effort to gain insights into his or her own genetic history, but third parties may seek to obtain this same information for other purposes. While federal law does not directly address consumer privacy issues relating to DTC genetic testing and there is no comprehensive federal law relating to collecting DNA samples or the sale of genetic information, several laws at the federal and state levels provide some protection for a person who submits to genetic testing.

Federal Laws

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) included the first federal regulations on the use of personal genetic information.¹⁰ HIPAA prohibits health insurers from using "preexisting condition" exclusions based solely on an individual's genetic information. Under HIPAA, insurers can make coverage decisions using information reflecting diagnosed health conditions, but not based on genetic indicators alone.¹¹

The Genetic Information Nondiscrimination Act of 2008 (GINA) extended federal patient protections by protecting a person from genetic discrimination in healthcare and employment. GINA prohibits a health insurance provider from using or requiring genetic information to make decisions about a person's insurance eligibility or coverage and prohibits an employer from using a person's genetic information when making decisions about hiring, promotion, and several other terms of employment.¹² However, the protections in GINA do not extend to other types of insurance, such as life insurance and long-term care insurance, and GINA only applies when an employer has more than 15 employees.¹³

The federal Patient Protection and Affordable Care Act¹⁴ (PPACA) prohibits most individual and group health insurers from excluding coverage to or otherwise discriminating against persons with pre-existing or complex health conditions. Moreover, the law prohibits plans from using most forms of medical underwriting, which had previously been used to link personal health status to the cost and availability of health insurance.¹⁵

Florida Law

⁸ *Id.*

⁹ FDA, *Direct-to-Consumer Test*, (Dec. 12, 2019) <https://www.fda.gov/medical-devices/itro-diagnostics/direct-consumer-tests#list> (last visited May 5, 2021).

¹⁰ Mark A. Hall and Rich S. Stephen, *Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination*. *AJHG* 66(1): 293-307, (Jan. 1, 2000) <https://doi.org/10.1086/302714> (last visited May 5, 2021).

¹¹ *Id.*

¹² U.S. Equal Employment Opportunity Commission, *The Genetic Information Nondiscrimination Act of 2008*, <https://www.eeoc.gov/laws/statutes/gina.cfm> (last visited May 5, 2021).

¹³ *Id.*

¹⁴ Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148. On March 30, 2010, PPACA was amended by the Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152.

¹⁵ 42 U.S.C. 300gg. The law allows insurers to consider an individual's age and tobacco use in the development of applicable rates. However, virtually all other underwriting is prohibited.

While federal law protects a person's genetic information only from misuse by a health insurer, in 2020, the Legislature expanded genetic information protections in Florida by amending s. 627.4301, F.S., to prohibit a health insurer, life insurer, or long-term care insurer from canceling, limiting, or denying coverage, and from setting different premium rates, based on a person's genetic information unless an insured person has a specific diagnosis related to genetic information.¹⁶ Such insurers are also prohibited from requiring or soliciting genetic information, using the results of any genetic testing a person may choose to complete, or considering a person's decisions or actions relating to genetic testing for any insurance purpose, unless he or she is diagnosed with a condition related to genetic information.¹⁷

Chapter 760, F.S., relates to civil rights and prohibits discrimination in the treatment of persons. Under s. 760.40, F.S., DNA analysis means the medical and biological examination and analysis of a person to identify the presence and composition of genes in his or her body and includes DNA typing and genetic testing. Unless a DNA analysis is used for determining paternity¹⁸ or entering a person's information into the Florida Department of Law Enforcement's (FDLE) criminal DNA database,¹⁹ a person commits a first degree misdemeanor by:

- Failing to get the informed consent of the person undergoing the analysis; or
- Misappropriating, failing to keep confidential, or disclosing without permission a person's DNA analysis results, regardless of whether such results are held by a public or private entity.²⁰

A person performing a DNA analysis or receiving records, results, or findings of a DNA analysis must provide the person tested with notice that the analysis was performed or that the information was received. The notice must state that the person tested may request that the information be given to his or her physician and whether the information was used in any decision to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity. If the information was used in any such decision, the DNA analysis must be repeated to verify the results, and if the first analysis is found to be inaccurate, the denial must be reviewed.²¹

Misuse of DNA

As the cost of genetic testing continues to drop and testing becomes increasingly available to the general public, instances of misusing another person's DNA have increased. For example, media sources have collected the DNA of public figures and celebrities without their consent to sell online; online companies offer to secretly test DNA samples in cases of suspected infidelity or disputed paternity; and blackmailers, nosy neighbors, or others may collect a person's DNA without consent for personal vengeance or malicious intent.²²

In a Florida case involving alleged defamation and a hate-mail campaign, an attorney created paper exhibits treated with chemicals designed to gather DNA from any person the paper touched. The attorney surreptitiously made sure the accused party touched such exhibits during a deposition and collected the accused party's used water bottles to perform a DNA analysis and compare the results to the DNA and fingerprints left on the hate mail.²³ The judge in the case stated that "no binding authority has ever definitively answered the question of whether genetic material such as DNA constitutes 'property.'"²⁴

¹⁶ Ch. 2020-159, Laws of Fla.

¹⁷ See also s. 626.9706, F.S., which prohibits insurers from refusing coverage or charging higher premiums to individuals determined to carry the sickle-cell trait.

¹⁸ As provided in ss. 409.256 or 742.12(1), F.S.

¹⁹ As provided in s. 943.325, F.S.

²⁰ S. 760.40(2)(a), F.S.

²¹ S. 760.40(3), F.S.

²² Elizabeth E. Joh, *DNA Theft: Recognizing the Crime of Nonconsensual Genetic Collection and Testing*, 91 B.U. L. Rev. 665, 670-972, (2011) <https://www.bu.edu/law/journals-archive/bulr/documents/joh.pdf> (last visited May 5, 2021).

²³ See *Douberley v. Perlmutter*, 219 So.3d 854, 855 (Fla. 4th DCA 2017).

²⁴ The Columbia Journal of Law & the Arts, *Marvel CEO's Litigation Quagmire Adds to DNA-Property Debate*, (Aug. 2, 2019) <https://journals.library.columbia.edu/index.php/lawandarts/announcement/view/56> (last visited May 5, 2021).

Although existing federal and state laws may protect a person's unique genetic material from being misused by insurance providers or for discriminatory purposes, no current law specifically protects a person's DNA from being collected or analyzed without his or her consent.

Effect of the Bill

The bill creates the "Protecting DNA Privacy Act" to define terms, change the level of consent currently required by a person for a lawful use of his or her DNA or disclosure of DNA analysis results, and create new crimes with increased penalties for collecting or retaining, submitting for analysis or analyzing, disclosing, or selling another person's DNA without his or her express consent.

The bill amends s. 760.40, F.S., to provide that "exclusive property" means a person's right to exercise control over his or her DNA sample or the results of his or her DNA analysis with regard to the collection, use, retention, maintenance, disclosure, or destruction of such sample or analysis results. Under the bill:

- "DNA analysis" means the medical and biological examination and analysis of a person's DNA to identify the presence and composition of genes in that person's body, and includes DNA typing and genetic testing; and
- "DNA sample" means any human biological specimen from which DNA can be extracted or the DNA extracted from such specimen.

The bill creates s. 817.5655, F.S., to prohibit a person from willfully and without express consent:

- Collecting or retaining another person's DNA sample with intent to analyze such sample, as a first degree misdemeanor;
- Submitting another person's DNA sample for analysis or conducting or procuring the conducting of such analysis, as a third degree felony;²⁵
- Disclosing another person's DNA analysis results to a third party, unless such results were previously voluntarily disclosed by the person whose DNA was analyzed, as a third degree felony; and
- Selling or otherwise transferring another person's DNA sample or analysis results to a third party, as a second degree felony.²⁶

Under the bill, express consent means a person's authorization, evidenced by an affirmative act which demonstrates his or her intentional decision, after receiving a clear and prominent disclosure regarding the specified purpose for the collection, use, retention, maintenance, or disclosure of the DNA sample or analysis thereof.

To ensure that a person who collects or retains a discarded item without intent to analyze another person's DNA obtained from the item will not be subject to a criminal penalty, the bill requires that an instance of unlawful collection or retention of another person's DNA be done with the intent to later perform a DNA analysis. A person who submits a DNA sample for analysis without express consent and a person that performs a DNA analysis or procures the performance of such analysis without express consent is guilty of an offense under the bill.

The bill authorizes a separate criminal penalty for each instance of unlawful collection or retention, submission or analysis, disclosure, or sale of a person's DNA sample or analysis results.

The bill applies only to the use, retention, maintenance and disclosure of a DNA sample collected from a person in Florida after the bill is effective. The bill does not apply to a DNA sample, analysis, or analysis results when used for specified purposes, including:

- Criminal investigation or prosecution;
- Complying with a subpoena, summons, or other lawful court order;
- Complying with Federal law;

²⁵ A third degree felony is punishable by up to five years in prison and a \$5,000 fine. Ss. 775.082 and 775.083, F.S.

²⁶ A second degree felony is punishable by up to 15 years in prison and a \$10,000 fine. Ss. 775.082 and 775.083, F.S.

- Medical diagnosis, quality assessment, improvement activity, and treatment of a patient when:
 - The health care practitioner who collected the DNA sample obtained express consent for clinical laboratory analysis of the DNA sample; or
 - Performed by a clinical laboratory certified by the Centers for Medicare and Medicaid Services.
- The newborn screening program under s. 383.14, F.S.;
- Determining paternity under s. 409.256, F.S. or s. 742.12(1), F.S.;
- Performing any activity authorized under s. 943.325; or
- Research activities conducted in compliance with applicable Federal laws and regulations which provide privacy protections for research subjects and designing and preparing such research, subject to the requirements of, and in compliance with, 45 C.F.R. part 46, 21 C.F.R. parts 50 and 56, or 45 C.F.R. parts 160 and 164; or utilizing information that is deidentified consistent with 45 C.F.R. parts 160 and 164 and that is originally collected and maintained for research subject to the requirements of, and in compliance with, 45 C.F.R. part 46, 21 C.F.R. parts 50 and 56, or 45 C.F.R. parts 160 and 164.

Subject to the Governor's veto powers, the effective date of this bill is October 1, 2021.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None.

2. Expenditures:

The bill may have an indeterminate positive impact on the number of prison beds by creating new felony crimes relating to unlawful use of DNA.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

See Fiscal Comments.

2. Expenditures:

See Fiscal Comments.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None.

D. FISCAL COMMENTS:

While the bill may have a negative impact on the number of jail beds by increasing the penalty for the crime of disclosing DNA analysis without consent from a misdemeanor to a felony, any negative impact is likely negated by the positive impact on the number of jail beds by the bill's new misdemeanor crime of unauthorized collection or retention of another person's DNA with intent to perform DNA analysis.