

## **State Statutes Declaring Genetic Information to be Personal Property<sup>1</sup>**

Seth Axelrad, ASLME Research Assistant

Four states—Alaska, Colorado, Florida, and Georgia—declare genetic information to be the personal property of the individual to which it pertains. Note that only Alaska expressly includes DNA samples as private property, although a broad interpretation of the phrase “genetic information” may include DNA or biological samples. The relevant statutory language is presented below:

1. Alaska: “[A] DNA sample and the results of a DNA analysis performed on the sample are the exclusive property of the person sampled or analyzed.” Alaska Stat. § 18.13.010(a)(2).
2. Colorado: “Genetic information is the unique property of the individual to whom the information pertains.” Colo. Rev. Stat. Ann. § 10-3-1104.7(1)(a).
3. Florida: “[T]he results of such DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested, are confidential, and may not be disclosed without the consent of the person tested.” Fla. Stat. Ann. § 760.40(2)(a).
4. Georgia: “Genetic information is the unique property of the individual tested.” Ga. Code Ann. § 33-54-1(1).

The Colorado and Georgia statutes are each part of its state insurance code. In general, these statutes prohibit the unauthorized testing and disclosure of individuals’ DNA for insurance purpose, and also prohibit discrimination in the provision of insurance services based on an individual’s genetic profile. The Florida statute, similar to the Colorado and Georgia statutes in requiring informed consent for DNA testing and disclosure, presents itself as a broader civil rights statute, applicable to discrimination in the areas of insurance, employment, mortgage, loan, credit, or educational opportunity. Alaska, like Florida, reaches a broader scope of conduct than Colorado and Georgia, yet differs due to its primary focus on health and medical issues.

The different focuses of the statutes underlie the different penalties established for violations of the genetic privacy provisions. Colorado and Georgia establish civil remedies—injunctive, monetary (including costs and attorneys’ fees), and/or specific relief (in the form of provision of insurance services)—when insurers have engaged in an “unfair practice.” Florida and Alaska, on the other hand, establish criminal penalties for violations of genetic privacy; arguably, in contrast to civil penalties, criminal penalties more effectively deter potential misuse or misappropriation of genetic information given the many contexts in which private information can be misused.

The state statutes are reproduced below:

### **Alaska**

---

<sup>1</sup> Funding for this research was provided to ASLME through the National Human Genome Research Institute, NIH, Grant No. 1 R01HG002836-01.

Alaska Stat. § 18.13.010 Genetic Testing

(a) Except as provided in (b) of this section,

(1) a person may not collect a DNA sample from a person, perform a DNA analysis on a sample, retain a DNA sample or the results of a DNA analysis, or disclose the results of a DNA analysis unless the person has first obtained the informed and written consent of the person, or the person's legal guardian or authorized representative, for the collection, analysis, retention, or disclosure;

(2) a DNA sample and the results of a DNA analysis performed on the sample are the exclusive property of the person sampled or analyzed.

(b) The prohibitions of (a) of this section do not apply to DNA samples collected and analyses conducted

(1) under AS 44.41.035 or comparable provisions of another jurisdiction;

(2) for a law enforcement purpose, including the identification of perpetrators and the investigation of crimes and the identification of missing or unidentified persons or deceased individuals;

(3) for determining paternity;

(4) to screen newborns as required by state or federal law;

(5) for the purpose of emergency medical treatment.

(c) A general authorization for the release of medical records or medical information may not be construed as the informed and written consent required by this section. The Department of Health and Social Services may by regulation adopt a uniform informed and written consent form to assist persons in meeting the requirements of this section. A person using that uniform informed and written consent is exempt from civil or criminal liability for actions taken under the consent form. A person may revoke or amend their informed and written consent at any time.

Alaska Stat. § 18.13.020 Private Right of Action

A person may bring a civil action against a person who collects a DNA sample from the person, performs a DNA analysis on a sample, retains a DNA sample or the results of a DNA analysis, or discloses the results of a DNA analysis in violation of this chapter. In addition to the actual damages suffered by the person, a person violating this chapter shall be liable to the person for damages in the amount of \$5,000 or, if the violation resulted in profit or monetary gain to the violator, \$100,000.

Alaska Stat. § 18.13.030 Criminal Penalty

(a) A person commits the crime of unlawful DNA collection, analysis, retention, or disclosure if the person knowingly collects a DNA sample from a person, performs a DNA analysis on a sample, retains a DNA sample or the results of a DNA analysis, or discloses the results of a DNA analysis in violation of this chapter.

(b) In this section, "knowingly" has the meaning given in AS 11.81.900.

(c) Unlawful DNA collection, analysis, retention, or disclosure is a class A misdemeanor.

Alaska Stat. § 18.13.100 Definitions

In this chapter,

(1) "DNA" means deoxyribonucleic acid, including mitochondrial DNA, complementary DNA, and DNA derived from ribonucleic acid;

(2) "DNA analysis" means DNA or genetic typing and testing to determine the presence or absence of genetic characteristics in an individual, including tests of nucleic acids or chromosomes in order to diagnose or identify a genetic characteristic; "DNA analysis" does not include a routine physical measurement, a test for drugs, alcohol, cholesterol, or the human immunodeficiency virus, a chemical, blood, or urine analysis, or any other diagnostic test that is widely accepted and in use in clinical practice;

(3) "genetic characteristic" includes a gene, chromosome, or alteration of a gene or chromosome that may be tested to determine the existence or risk of a disease, disorder, trait, propensity, or syndrome, or to identify an individual or a blood relative; "genetic characteristic" does not include family history or a genetically transmitted characteristic whose existence or identity is determined other than through a genetic test.

**Colorado**

Colo. Rev. Stat. Ann. § 10-3-1104.7 Genetic testing

(1) The general assembly hereby finds and determines that recent advances in genetic science have led to improvements in the diagnosis, treatment, and understanding of a significant number of human diseases. The general assembly further declares that:

(a) Genetic information is the unique property of the individual to whom the information pertains;

(b) Any information concerning an individual obtained through the use of genetic techniques may be subject to abuses if disclosed to unauthorized third parties without the willing consent of the individual to whom the information pertains;

(c) To protect individual privacy and to preserve individual autonomy with regard to the individual's genetic information, it is appropriate to limit the use and availability of genetic information;

(d) The intent of this statute is to prevent information derived from genetic testing from being used to deny access to health care insurance, group disability insurance, or long-term care insurance coverage.

(2) For the purposes of this section:

(a) "Entity" means any sickness and accident insurance company, health maintenance organization, nonprofit hospital, medical-surgical and health service corporation, or other entity that provides health care insurance, group disability insurance, or long-term care insurance coverage and is subject to the jurisdiction of the commissioner of insurance.

(b) "Genetic testing" means any laboratory test of human DNA, RNA, or chromosomes that is used to identify the presence or absence of alterations in genetic material which are associated with disease or illness. "Genetic testing" includes only such tests as are direct measures of such alterations rather than indirect manifestations thereof.

(3)(a) Information derived from genetic testing shall be confidential and privileged. Any release, for purposes other than diagnosis, treatment, or therapy, of genetic testing information that identifies the person tested with the test results released requires specific written consent by the person tested.

(b) Any entity that receives information derived from genetic testing may not seek, use, or keep the information for any nontherapeutic purpose or for any underwriting purpose connected with the provision of health care insurance, group disability insurance, or long-term care insurance coverage.

(4) Notwithstanding the provisions of subsection (3) of this section, in the course of a criminal investigation or a criminal prosecution, and to the extent allowed under the federal or state constitution, any peace officer, district attorney, or assistant attorney general, or a designee thereof, may obtain information derived from genetic testing regarding the identity of any individual who is the subject of the criminal investigation or prosecution for use exclusively in the criminal investigation or prosecution without the consent of the individual being tested.

(5) Notwithstanding the provisions of subsection (3) of this section, any research facility may use the information derived from genetic testing for scientific research purposes so long as the identity of any individual to whom the information pertains is not disclosed to any third party; except that the individual's identity may be disclosed to the individual's physician if the individual consents to such disclosure in writing.

(6) This section does not limit the authority of a court or any party to a parentage proceeding to use information obtained from genetic testing for purposes of determining parentage pursuant to section 13-25-126, C.R.S.

(7) This section does not limit the authority of a court or any party to a proceeding that is subject to the limitations of part 5 of article 64 of title 13, C.R.S. [FN1], to use information obtained from genetic testing for purposes of determining the cause of damage or injury.

(8) This section does not limit the authority of the state board of parole to require any offender who is involved in a sexual assault to submit to blood tests and to retain the results of such tests on file as authorized under section 17-2-201(5)(g), C.R.S.

(9) This section does not limit the authority granted the state department of public health and environment, the state board of health, or local departments of health pursuant to section 25-1-122, C.R.S.

(10) Notwithstanding any provision of this section to the contrary, the only requirements that shall apply to an insurer in connection with life insurance or individual disability insurance are as follows:

(a) Except as otherwise specifically authorized or required by another section of state or federal law, an insurer shall not require the performance of or perform a genetic test without first receiving the specific, written, informed consent of the subject of the test who has the capacity to consent or, if the person subject to the test lacks the capacity to consent, of a person authorized by law to consent on behalf of the subject of the test. Written consent shall be in a form prescribed by the commissioner.

(b) The results of a genetic test performed pursuant to this subsection (10) are privileged and confidential and shall not be released to any person except as specifically authorized under applicable state or federal law.

(11) Any violation of this section is an "unfair practice", as defined in section 10-3-1104(1), and is subject to the provisions of sections 10-3-1106 to 10-3-1113.

(12) Any individual who is injured by an entity's violation of this section may recover in a court of competent jurisdiction the following remedies:

(a) Equitable relief, which may include a retroactive order, directing the entity to provide health insurance, group disability insurance, or long-term care insurance coverage, whichever is appropriate, to the injured individual under the same terms and conditions as would have applied had the violation not occurred; and

(b) The greater of:

(I) An amount equal to any actual damages suffered by the individual as a result of the

violation; or

(II) Ten thousand dollars per violation.

(13) The prevailing party in an action under this section may recover costs and reasonable attorney fees.

## **Florida**

### Fla. Stat. Ann. 760.40. Genetic testing; informed consent; confidentiality; penalties; notice of use of results

(1) As used in this section, the term "DNA analysis" means the medical and biological examination and analysis of a person to identify the presence and composition of genes in that person's body. The term includes DNA typing and genetic testing.

(2)(a) Except for purposes of criminal prosecution, except for purposes of determining paternity as provided in s. 742.12(1), and except for purposes of acquiring specimens from persons convicted of certain offenses or as otherwise provided in s. 943.325, DNA analysis may be performed only with the informed consent of the person to be tested, and the results of such DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested, are confidential, and may not be disclosed without the consent of the person tested. Such information held by a public entity is exempt from the provisions of s. 119.07(1) and s. 24(a), Art. I of the State Constitution.

(b) A person who violates paragraph (a) is guilty of a misdemeanor of the first degree, punishable as provided in s. 775.082 or s. 775.083.

(3) A person who performs DNA analysis or receives records, results, or findings of 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, upon the request of the person tested, the information will be made available to his or her physician. The notice must also state 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 decision that resulted in a denial, the analysis must be repeated to verify the accuracy of the first analysis, and if the first analysis is found to be inaccurate, the denial must be reviewed.

## **Georgia**

### Ga. Code Ann. § 33-54-1 Legislative intent

The General Assembly finds and determines that recent advances in genetic science have led to improvements in the diagnosis, treatment, and understanding of a significant number of human diseases. The General Assembly further finds and declares that:

- (1) Genetic information is the unique property of the individual tested;
- (2) The use and availability of information concerning an individual obtained through the use of genetic testing techniques may be subject to abuses if disclosed to unauthorized third parties without the willing consent of the individual tested;
- (3) To protect individual privacy and to preserve individual autonomy with regard to an individual's genetic information, it is appropriate to limit the use and availability of genetic information; and
- (4) The intent of this chapter is to prevent accident and sickness insurance companies, health maintenance organizations, managed care organizations, and other payors from using information derived from genetic testing to deny access to accident and sickness insurance.

#### Ga. Code Ann. § 33-54-2 Definitions

As used in this chapter, the term:

- (1) "Genetic testing" means laboratory tests of human DNA or chromosomes for the purpose of identifying the presence or absence of inherited alterations in genetic material or genes which are associated with a disease or illness that is asymptomatic at the time of testing and that arises solely as a result of such abnormality in genes or genetic material. For purposes of this chapter, genetic testing shall not include routine physical measurements; chemical, blood, and urine analysis; tests for abuse of drugs; and tests for the presence of the human immunodeficiency virus.
- (2) "Insurer" means an insurer, a fraternal benefit society, a nonprofit medical service corporation, a health care corporation, a health maintenance corporation, or a self-insured health plan not subject to the exclusive jurisdiction of the Employee Retirement Income Security Act of 1974, 29 U.S.C. Section 1001, et seq.

#### Ga. Code Ann. § 33-54-3 Purposes for which genetic testing may be conducted; consent to testing; confidentiality of information

- (a) Except as otherwise provided in this chapter, genetic testing may only be conducted to obtain information for therapeutic or diagnostic purposes. Genetic testing may not be conducted without the prior written consent of the person to be tested.
- (b) Information derived from genetic testing shall be confidential and privileged and may be released only to the individual tested and to persons specifically authorized by such individual to receive the information. Any insurer that possesses information derived from genetic testing may not release the information to any third party without the explicit written consent of the individual tested. Information derived from genetic testing may not be sought by any insurer as defined in Code Section 33-54-2.

Ga. Code Ann. § 33-54-4 Prohibited use of information received by insurer

Any insurer that receives information derived from genetic testing may not use the information for any nontherapeutic purpose.

Ga. Code Ann. § 33-54-5 Disclosure to law enforcement agencies of information regarding identity of individuals subject to criminal investigation or prosecution

Notwithstanding the provisions of Code Sections 33-54-3 and 33-54-4, information derived from genetic testing regarding the identity of any individual who is the subject of a criminal investigation or a criminal prosecution may be disclosed to appropriate legal authorities conducting the investigation or prosecution. The information may be used during the course of the investigation or prosecution with respect to the individual tested without the consent of such individual.

Ga. Code Ann. § 33-54-6 Use of information for scientific research purposes

Notwithstanding the provisions of Code Sections 33-54-3 and 33-54-4, any research facility may conduct genetic testing and may use the information derived from genetic testing for scientific research purposes so long as the identity of any individual tested is not disclosed to any third party, except that the individual's identity may be disclosed to the individual's physician with the consent of the individual.

Ga. Code Ann. § 33-54-7 Exception of certain insurance policies

This chapter shall not apply to a life insurance policy, disability income policy, accidental death or dismemberment policy, medicare supplement policy, long-term care insurance policy, credit insurance policy, specified disease policy, hospital indemnity policy, blanket accident and sickness policy, franchise policy issued on an individual basis to members of an association, limited accident policy, health insurance policy written as a part of workers' compensation equivalent coverage, or other similar limited accident and sickness policy.

Ga. Code Ann. § 33-54-8 Civil penalties

(a) Any violation of this chapter by an insurer shall be unfair trade practice subject to the provisions of Article 1 of Chapter 6 of this title, and a violation of this chapter by any other person shall be an unfair practice and shall be subject to the provisions of Part 2 of Article 15 of Chapter 1 of Title 10, the "Fair Business Practices Act of 1975." In addition, any individual who is harmed as a result of a violation of this chapter shall have a cause of action against the person whose violation caused the harm.

(b) Any insurer that is found in violation of the provisions of this chapter by a court of competent jurisdiction is liable to the individual injured by the violation in an amount equal to any actual damages suffered by the individual. In the alternative, the court may issue an order directing the insurer to provide accident and sickness insurance to the

injured individual under the same terms and conditions as would have applied had the violation not occurred.

(c) The court shall award costs and reasonable attorney's fees to any individual who is successful in enforcing the provision of this chapter.