HB78
135192-1
By Representative Henry
RFD: Health
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SYNOPSIS: This bill would be known as the Genetic Information Privacy Act.

This bill would provide for definitions and scope.

This bill would require informed consent in order to obtain, access, analyze, and disclose of genetic information.

This bill would require authorization for the collection and storage of DNA samples used for genetic analysis.

This bill would not alter any parents' rights to the medical or genetic test results of their children.

This bill would provide for penalties for unlawful disclosure of genetic information.

Amendment 621 of the Constitution of Alabama of 1901, now appearing as Section 111.05 of the Official Recompilation of the Constitution of Alabama of 1901, as amended, prohibits a general law whose purpose or effect would be to require a
new or increased expenditure of local funds from
becoming effective with regard to a local
governmental entity without enactment by a 2/3 vote
unless: it comes within one of a number of
specified exceptions; it is approved by the
affected entity; or the Legislature appropriates
funds, or provides a local source of revenue, to
the entity for the purpose.

The purpose or effect of this bill would be
to require a new or increased expenditure of local
funds within the meaning of the amendment. However,
the bill does not require approval of a local
governmental entity or enactment by a 2/3 vote to
become effective because it comes within one of the
specified exceptions contained in the amendment.

A BILL
TO BE ENTITLED
AN ACT

Relating to genetic information; to provide for
definitions and scope; to require certain information in order
to obtain, disclose, access, collect, or share genetic
information; and to provide penalties for unlawful disclosure;
and in connection therewith would have as its purpose or
effect the requirement of a new or increased expenditure of
local funds within the meaning of Amendment 621 of the
Constitution of Alabama of 1901, now appearing as Section 111.05 of the Official Recompilation of the Constitution of Alabama of 1901, as amended.

BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

Section 1. This act may be known as the Genetic Information Privacy Act.

Section 2. As used in this act, the following terms shall have the following meanings:

(1) GENETIC CHARACTERISTIC. Any inherited gene or chromosome, or alteration thereof, that is scientifically or medically believed to predispose an individual to a disease, disorder, or syndrome, or to be associated with a statistically significant increased risk of development of a disease, disorder, or syndrome, including, but not limited to, information regarding carrier status, information regarding an increased likelihood of future disease or increased sensitivity to any substance, information derived from laboratory tests that identify mutations in specific genes or chromosomes, requests for genetic services or counseling, tests of gene products, and direct analysis of genes or chromosomes.

(2) GENETIC INFORMATION. Information about inherited genes or chromosomes, including nucleic acids such as DNA, RNA, and mitochondrial DNA, chromosomes or proteins, and of alterations thereof, whether obtained from an individual or family member, that is scientifically or medically believed to predispose an individual to disease, disorder, or syndrome or
believed to be associated with a statistically significant
increased risk of development of a disease, disorder, or
syndrome, and that it is also the personal property of whom it
is taken.

(3) GENETIC TEST. A test for determining the
presence or absence of an inherited genetic characteristic in
an individual, including tests of nucleic acids such as DNA,
RNA, and mitochondrial DNA, chromosomes or proteins in order
to identify a predisposing genetic characteristic associated
with disease, disorder, or syndrome.

(4) INFORMED CONSENT. a. For the purpose of
obtaining genetic information, means the signing of a consent
form which includes a description of the genetic test to be
performed, its purposes, potential uses, and limitations and
the meaning of its results, and that the individual shall
receive the results unless the individual directs otherwise.

b. For the purpose of retaining genetic information,
means the signing of a consent form which includes a
description of the genetic information to be retained, its
potential uses, and limitations.

c. For the purpose of disclosing genetic
information, means the signing of a consent form which
includes a description of the genetic information to be
disclosed and to whom.

d. For the purpose of obtaining insurance, there may
be a single signing which shall allow the obtaining,
retaining, and disclosure of genetic information, which, in
addition to the requirements of paragraphs a. and b. of this subsection, shall:

1. Be written in plain language.
2. Be dated.
3. Name or identify by generic reference the persons authorized to disclose information about the individual.
4. Specify the nature of the information authorized to be disclosed.
5. Name or identify by generic reference the person to whom the individual is authorizing information to be disclosed or subsequently re-disclosed.
6. Describe the purpose for which the information is collected.
7. Specify the length of time such authorization shall remain valid.
8. Be signed by:
   (i) The individual.
   (ii) Such other person authorized to consent for such individual, if such individual lacks the capacity to consent.
   (iii) The claimant for the proceeds of an insurance policy.

Section 3. (a) No person may collect or cause to be collected an individually identifiable DNA sample for genetic analysis without the written authorization of the sample source or the sample source's representative.
(b) The requirements of this section shall not apply to genetic information obtained:

(1) By a state, county, municipal, or federal law enforcement agency for the purposes of establishing the identity of a person in the course of a criminal investigation or prosecution.

(2) To determine paternity.

(3) To determine the identity of deceased individuals.

(4) For anonymous research where the identity of the subject will not be released.

(5) Pursuant to newborn screening requirements established by state or federal law.

(6) As authorized by federal law for the identification of persons.

(c) Prior to the collection of a DNA sample from a sample source for genetic analysis, the person collecting the sample or causing the sample to be collected shall verbally inform the sample source or the sample source's representative of the following:

(1) Consent that the collection or taking of the DNA sample is voluntary.

(2) Consent that the genetic analysis is voluntary.

(3) Information that can reasonably be expected to be derived from the genetic analysis.
(4) The use, if any, that the sample source or the sample source's representative will be able to make of the information derived from the genetic analysis.

(5) The right to inspect records that contain information derived from the genetic analysis.

(6) The right to have the DNA sample destroyed.

(7) The right to revoke consent to the genetic analysis at any time prior to the completion of the analysis.

(8) The genetic analysis may result in information about the sample source's genetic relatives which may not be known to such relatives but could be important, and if so, it will be the sample source's decision whether or not to share that information with relatives.

(9) In the future, someone else may ask if the sample source has obtained genetic testing or analysis and condition of a benefit on the disclosure of information regarding such testing or analysis.

(10) The collection and analysis of the DNA sample and the private genetic information derived from the analysis is protected by this act.

(11) The availability of genetic counseling.

Section 4. (a) Genetic analysis of an individually identifiable DNA sample is prohibited unless specifically authorized in writing by the sample source or the sample source's representative.
(b) No person may analyze an individually identifiable DNA sample without ascertaining that written authorization for the analysis has been obtained.

Section 5. (a) To be valid, the authorization required by Sections 3 and 4 must satisfy each of the following requirements:

(1) Be in writing signed by the sample source or the sample source’s representative and dated on the date of the signature.

(2) Identify the person who collects the DNA sample or causes the DNA sample to be collected.

(3) Identify the facility in which the analysis is to be performed.

(4) Identify the facility in which the DNA sample is to be stored.

(5) State the manner in which the sample is to be collected.

(6) Include a description of all authorized uses of the DNA sample.

(7) Indicate whether or not the sample source permits the sample to be maintained or stored in an identifiable form after the analysis is completed.

(8) Include a provision that enables the sample source or the sample source's representative to prohibit the use of the DNA sample for research or commercial purposes even if the sample is not in an individually identifiable form.
(b) The authorization for the collection and analysis of an individually identifiable DNA sample shall be retained at least as long as the DNA sample is retained.

(c) A copy of the authorization shall be provided to the sample source or the sample source's representative.

Section 6. (a) Regardless of the manner of receipt or the source of genetic information, including information received from an individual, a person shall not disclose or be compelled, by subpoena or any other means, to disclose the identity of an individual upon whom a genetic test has been performed, or to disclose genetic information about the individual in a manner that permits identification of the individual, unless the following apply:

(1) Disclosure is necessary for the purposes of a criminal or death investigation or a criminal or juvenile proceeding or to protect the interests of an issuer in the detection or prevention of fraud, material misrepresentation, or material nondisclosure.

(2) Disclosure is necessary to determine paternity.

(3) Disclosure is authorized by order of a court of competent jurisdiction.

(4) Disclosure is authorized by obtaining informed consent of the tested individual describing the information to be disclosed and to whom.

(5) Disclosure is for the purpose of furnishing genetic information relating to a decedent for medical diagnosis of blood relatives of the decedent.
(6) Disclosure is for the purpose of identifying bodies.

(7) Disclosure is pursuant to newborn screening requirements established by state or federal law.

(8) Disclosure is authorized by federal law for the identification of persons.

(9) Disclosure is by an insurer to an insurance regulatory authority.

(10) Disclosure is otherwise permitted by law.

Section 7. This act does not alter any right of parents or guardians to order medical or genetic tests, or both, of their children.

Section 8. (a) Any person who willfully retains an individual's genetic information or retains an individual's sample in violation of this act shall be punished by a fine of not less than one thousand dollars ($1,000) nor more than ten thousand dollars ($10,000).

(b) Any person who willfully obtains or discloses genetic information in violation of this act shall be punished by a fine of not less than five thousand dollars ($5,000) nor more than fifty thousand dollars ($50,000).

(c) Any person who willfully discloses an individual's genetic information in violation of this act shall be liable to the individual for all actual damages, including damages for economic, bodily, or emotional harm which is proximately caused by the disclosure.
(d) The circuit court shall have jurisdiction over all violations of this act.

Section 9. (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 act.

(b) Unlawful DNA collection, analysis, retention, or disclosure is a Class A misdemeanor.

Section 10. A DNA sample and the results of a DNA analysis performed on the sample are the exclusive property of the person sampled or analyzed.

Section 11. Although this bill would have as its purpose or effect the requirement of a new or increased expenditure of local funds, the bill is excluded from further requirements and application under Amendment 621, now appearing as Section 111.05 of the Official Recompilation of the Constitution of Alabama of 1901, as amended, because the bill defines a new crime or amends the definition of an existing crime.

Section 12. This act shall become effective on the first day of the third month following its passage and approval by the Governor, or its otherwise becoming law.