

1 HB78
2 135192-1
3 By Representative Henry
4 RFD: Health
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6 PFD: 01/23/2012

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8 SYNOPSIS: This bill would be known as the Genetic
9 Information Privacy Act.

10 This bill would provide for definitions and
11 scope.

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

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

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

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

23 Amendment 621 of the Constitution of Alabama
24 of 1901, now appearing as Section 111.05 of the
25 Official Recompilation of the Constitution of
26 Alabama of 1901, as amended, prohibits a general
27 law whose purpose or effect would be to require a

1 new or increased expenditure of local funds from
2 becoming effective with regard to a local
3 governmental entity without enactment by a 2/3 vote
4 unless: it comes within one of a number of
5 specified exceptions; it is approved by the
6 affected entity; or the Legislature appropriates
7 funds, or provides a local source of revenue, to
8 the entity for the purpose.

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

16
17 A BILL
18 TO BE ENTITLED
19 AN ACT
20

21 Relating to genetic information; to provide for
22 definitions and scope; to require certain information in order
23 to obtain, disclose, access, collect, or share genetic
24 information; and to provide penalties for unlawful disclosure;
25 and in connection therewith would have as its purpose or
26 effect the requirement of a new or increased expenditure of
27 local funds within the meaning of Amendment 621 of the

1 Constitution of Alabama of 1901, now appearing as Section
2 111.05 of the Official ReCompilation of the Constitution of
3 Alabama of 1901, as amended.

4 BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

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

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

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

22 (2) GENETIC INFORMATION. Information about inherited
23 genes or chromosomes, including nucleic acids such as DNA,
24 RNA, and mitochondrial DNA, chromosomes or proteins, and of
25 alterations thereof, whether obtained from an individual or
26 family member, that is scientifically or medically believed to
27 predispose an individual to disease, disorder, or syndrome or

1 believed to be associated with a statistically significant
2 increased risk of development of a disease, disorder, or
3 syndrome, and that it is also the personal property of whom it
4 is taken.

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

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

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

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

25 d. For the purpose of obtaining insurance, there may
26 be a single signing which shall allow the obtaining,
27 retaining, and disclosure of genetic information, which, in

1 addition to the requirements of paragraphs a. and b. of this
2 subsection, shall:

3 1. Be written in plain language.

4 2. Be dated.

5 3. Name or identify by generic reference the persons
6 authorized to disclose information about the individual.

7 4. Specify the nature of the information authorized
8 to be disclosed.

9 5. Name or identify by generic reference the person
10 to whom the individual is authorizing information to be
11 disclosed or subsequently re-disclosed.

12 6. Describe the purpose for which the information is
13 collected.

14 7. Specify the length of time such authorization
15 shall remain valid.

16 8. Be signed by:

17 (i) The individual.

18 (ii) Such other person authorized to consent for
19 such individual, if such individual lacks the capacity to
20 consent.

21 (iii) The claimant for the proceeds of an insurance
22 policy.

23 Section 3. (a) No person may collect or cause to be
24 collected an individually identifiable DNA sample for genetic
25 analysis without the written authorization of the sample
26 source or the sample source's representative.

1 (b) The requirements of this section shall not apply
2 to genetic information obtained:

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

7 (2) To determine paternity.

8 (3) To determine the identity of deceased
9 individuals.

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

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

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

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

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

23 (2) Consent that the genetic analysis is voluntary.

24 (3) Information that can reasonably be expected to
25 be derived from the genetic analysis.

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

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

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

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

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

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

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

21 (11) The availability of genetic counseling.

22 Section 4. (a) Genetic analysis of an individually
23 identifiable DNA sample is prohibited unless specifically
24 authorized in writing by the sample source or the sample
25 source's representative.

1 (b) No person may analyze an individually
2 identifiable DNA sample without ascertaining that written
3 authorization for the analysis has been obtained.

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

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

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

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

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

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

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

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

23 (8) Include a provision that enables the sample
24 source or the sample source's representative to prohibit the
25 use of the DNA sample for research or commercial purposes even
26 if the sample is not in an individually identifiable form.

1 (b) The authorization for the collection and
2 analysis of an individually identifiable DNA sample shall be
3 retained at least as long as the DNA sample is retained.

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

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

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

19 (2) Disclosure is necessary to determine paternity.

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

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

25 (5) Disclosure is for the purpose of furnishing
26 genetic information relating to a decedent for medical
27 diagnosis of blood relatives of the decedent.

1 (6) Disclosure is for the purpose of identifying
2 bodies.

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

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

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

9 (10) Disclosure is otherwise permitted by law.

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

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

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

22 (c) Any person who willfully discloses an
23 individual's genetic information in violation of this act
24 shall be liable to the individual for all actual damages,
25 including damages for economic, bodily, or emotional harm
26 which is proximately caused by the disclosure.

1 (d) The circuit court shall have jurisdiction over
2 all violations of this act.

3 Section 9. (a) A person commits the crime of
4 unlawful DNA collection, analysis, retention, or disclosure if
5 the person knowingly collects a DNA sample from a person,
6 performs a DNA analysis on a sample, retains a DNA sample or
7 the results of a DNA analysis, or discloses the results of a
8 DNA analysis in violation of this act.

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

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

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

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