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State of Minnesota

HOUSE OF REPRESENTATIVES

NINETY-FIRST SESSION

H. F. No. 112

01/17/2019 Authored by Lucero, Scott, Lesch, Franson, Albright and others
The bill was read for the first time and referred to the Judiciary Finance and Civil Law Division

1.1 A bill for an act
1.2 relating to genetic information; modifying existing law on the use of genetic
1.3 information by government entities; creating new consumer protection law
1.4 regarding use of genetic information; amending Minnesota Statutes 2018, section
1.5 13.386; proposing coding for new law in Minnesota Statutes, chapter 325F.

1.6 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

1.7 Section 1. Minnesota Statutes 2018, section 13.386, is amended to read:

1.8 13.386 TREATMENT OF GENETIC INFORMATION HELD BY GOVERNMENT
1.9 ENTITIES AND OTHER PERSONS.

1.10 Subdivision 1. Definition. (a) "Genetic information" means information about an
1.11 identifiable individual derived from the presence, absence, alteration, or mutation of a gene,
1.12 or the presence or absence of a specific DNA or RNA marker, which has been obtained
1.13 from an analysis of:

- 1.14 (1) the individual's biological information or specimen; or
1.15 (2) the biological information or specimen of a person to whom the individual is related.

1.16 Genetic information is about an individual if it identifies an individual or if it describes any
1.17 characteristic that could uniquely identify an individual.

1.18 (b) "Genetic information" also means medical or biological information collected from
1.19 an individual about a particular genetic condition that is or might be used to provide medical
1.20 care to that individual or the individual's family members.

1.21 Subd. 2. Private data. Genetic information held by a government entity is private data
1.22 on individuals as defined by section 13.02, subdivision 12.

2.1 Subd. 3. **Collection, storage, use, and dissemination of genetic information.** (a) Unless
 2.2 otherwise expressly provided by law, genetic information about an individual:

2.3 (1) may be collected by a government entity, as defined in section 13.02, subdivision
 2.4 7a, ~~or any other person~~ only with the written informed consent of the individual;

2.5 (2) may be used only for purposes to which the individual has given written informed
 2.6 consent;

2.7 (3) may be stored only for a period of time to which the individual has given written
 2.8 informed consent; and

2.9 (4) may be disseminated only:

2.10 (i) with the individual's written informed consent; or

2.11 (ii) if necessary in order to accomplish purposes described by clause (2). ~~A consent to~~
 2.12 ~~disseminate genetic information under item (i) must be signed and dated.~~

2.13 (b) In order to be effective under this subdivision, an informed consent must:

2.14 (1) include the Tennessee warning required by section 13.04;

2.15 (2) be understandable to a person of average intelligence and education;

2.16 (3) be specific as to:

2.17 (i) the identity of the government entity or entities the individual is authorizing to collect,
 2.18 use, store, or disseminate the genetic information;

2.19 (ii) the nature of the genetic information the government entity intends to collect, use,
 2.20 store, or disseminate;

2.21 (iii) the identity of any persons to whom the government entity intends to disseminate
 2.22 the genetic information; and

2.23 (iv) the purposes for which the genetic information may be used by the government
 2.24 entity or by any persons identified under clause (iii); and

2.25 (4) be signed and dated.

2.26 (c) Unless otherwise provided by law, such a consent an informed consent under this
 2.27 subdivision is valid for one year or for a lesser period specified in the consent.

2.28 ~~(b)~~ (d) Newborn screening activities conducted under sections 144.125 to 144.128 are
 2.29 subject to paragraph (a) this subdivision. Other programs and activities governed under
 2.30 section 144.192 are not subject to paragraph (a) this subdivision.

3.1 Sec. 2. [325F.786] GENETIC INFORMATION.

3.2 Subdivision 1. Scope; exclusions. This section does not apply to:

3.3 (1) a government entity subject to section 13.386 or 144.192; or

3.4 (2) a health care provider as defined in section 144.291, subdivision 2, paragraph (i).

3.5 Subd. 2. Definition. "Genetic information" has the meaning given in section 13.386,
3.6 subdivision 1.

3.7 Subd. 3. Collection, storage, use, and dissemination of genetic information. (a) An
3.8 individual's genetic information and any biological specimen analyzed to obtain that genetic
3.9 information is the exclusive property of the individual.

3.10 (b) Unless otherwise expressly provided by law, a person that collects, creates, receives,
3.11 maintains, or disseminates genetic information about an individual may:

3.12 (1) collect the information only with the written informed consent of the individual;

3.13 (2) use the information only for purposes to which the individual has given written
3.14 informed consent;

3.15 (3) store the information only for a period of time to which the individual has given
3.16 written informed consent; and

3.17 (4) disseminate the information only:

3.18 (i) with the individual's written informed consent; or

3.19 (ii) if necessary in order to accomplish purposes described by clause (2).

3.20 (c) In order to be effective under this subdivision, an informed consent must:

3.21 (1) be understandable to a person of average intelligence and education;

3.22 (2) be specific as to:

3.23 (i) the identity of the person the individual is authorizing to collect, use, store, or
3.24 disseminate the genetic information;

3.25 (ii) the nature of the genetic information that the person intends to collect, use, store, or
3.26 disseminate;

3.27 (iii) the identity of any additional persons to whom the person intends to disseminate
3.28 the genetic information; and

3.29 (iv) the purposes for which the genetic information may be used by the person or by any
3.30 additional persons identified under clause (iii); and

4.1 (3) be signed and dated.

4.2 (c) Unless otherwise provided by law, an informed consent under this subdivision is
4.3 valid for one year or for a lesser period specified in the consent.

4.4 Subd. 4. **Enforcement.** Any person injured by a violation of this section may bring a
4.5 civil action to enforce this section and recover any actual damages, costs and disbursements,
4.6 including reasonable attorney fees incurred in the civil action. In addition to the remedies
4.7 provided in this section, the attorney general may bring an action pursuant to section 8.31
4.8 against any person for violation of this section.