

SENATE BILL NO. 66

January 28, 1997, Introduced by Senators A. SMITH and BYRUM
and referred to the Committee on Financial Services.

A bill to regulate access to genetic information about
individuals.

THE PEOPLE OF THE STATE OF MICHIGAN ENACT:

1 Sec. 1. This act shall be known and may be cited as the
2 "genetic information privacy act".

3 Sec. 2. As used in this act:

4 (a) "DNA sample" means a deoxyribonucleic acid specimen
5 taken from an individual.

6 (b) "Genetic information" means data derived from an indi-
7 vidual or member of the individual's family about the
8 individual's genes, gene products, or inherited characteristics.

9 (c) "Genetic test" means a procedure for determining the
10 presence or absence of an inherited genetic characteristic in an
11 individual, and includes but is not limited to a test of
12 chromosomes, proteins, or nucleic acids such as DNA, RNA, or

1 mitochondrial DNA to identify a predisposing genetic
2 characteristic.

3 (d) "Individual" means a natural person.

4 (e) "Person" means an individual, partnership, corporation,
5 association, governmental entity, or other legal entity.

6 (f) "RNA" means nucleic acids that contain ribose and uracil
7 as structural components and are associated with the control of
8 cellular chemical activities.

9 Sec. 3. (1) A person shall not perform a genetic test upon
10 an individual unless the person provides the individual with
11 written notice that contains a specific description of the test
12 to be performed and includes a statement that identifies all of
13 the following:

14 (a) The purpose of the test.

15 (b) The potential uses of the test.

16 (c) The limitations of the test.

17 (d) The meaning of any results of the test.

18 (e) The procedures for providing the individual with notice
19 of the test results.

20 (f) The rights of the individual to keep the test results
21 confidential, subject to the exceptions specified in this act.

22 (2) A person who performs a genetic test performed upon an
23 individual or who receives the results of a genetic test per-
24 formed upon that individual shall provide the individual with a
25 statement specifying that the test was performed or that the test
26 results were received. The statement shall include a notice that
27 genetic information derived from the test may not be disclosed to

1 persons other than the individual without the individual's
2 written consent, unless the disclosure is made in accordance with
3 an exception specified in this act.

4 (3) This subsection does not apply to an individual who
5 orders a genetic test or receives the results of a genetic test
6 performed on himself or herself.

7 (4) A person who violates this section is guilty of a misde-
8 meanor punishable by a fine of \$1,000.00 or imprisonment for not
9 more than 6 months, or both.

10 Sec. 4. (1) Genetic information about an individual is the
11 property of the individual. A person other than the individual
12 shall not obtain the individual's genetic information without the
13 express written consent of the individual unless the genetic
14 information is required for 1 or more of the following purposes:

15 (a) To establish the identity of an individual by a law
16 enforcement agency engaged in a criminal investigation, or by a
17 court in a juvenile or criminal adjudication or proceeding.

18 (b) To establish the identity of an individual if the acqui-
19 sition of the genetic information is authorized by federal or
20 state law.

21 (c) To comply with newborn screening requirements estab-
22 lished by federal or state law.

23 (d) To determine paternity in accordance with the paternity
24 act, 1956 PA 205, MCL 722.711 to 722.730.

25 (e) To determine the identity of a deceased individual.

26 (f) To conduct research in which the identity of the
27 individual remains anonymous.

1 (2) A person who violates this section is guilty of a
2 misdemeanor punishable by a fine of \$1,000.00 or imprisonment for
3 not more than 6 months, or both.

4 Sec. 5. (1) A person who obtains possession of an
5 individual's genetic information shall not retain that genetic
6 information without the express written consent of the individu-
7 al, unless the retention is required to achieve 1 or more of the
8 purposes described in section 4. The person shall not retain the
9 genetic information after a purpose described in section 4 is
10 achieved unless the individual about whom the genetic information
11 relates expressly consents in writing to the retention.

12 (2) A DNA sample shall be destroyed promptly after per-
13 formance of the genetic test for which the sample was taken,
14 unless 1 of the following conditions is met:

15 (a) Retention is required for an ongoing criminal investiga-
16 tion, or for a criminal or juvenile adjudication or proceeding.

17 (b) Retention is authorized by a court having jurisdiction.

18 (3) An individual's DNA sample provided for a research
19 project shall be destroyed immediately after completion of the
20 project or upon withdrawal of the individual from the project,
21 whichever occurs first. However, this subsection does not apply
22 if the individual or his or her representative expressly consents
23 to retention of the sample after receiving explicit information
24 about the purpose of that retention.

25 (4) An individual's DNA sample provided for an insurance or
26 employment purpose shall be destroyed immediately after that

1 purpose is met, unless the destruction is prohibited by a court
2 order.

3 (5) A person who violates this section is guilty of a misde-
4 meanor punishable by a fine of \$1,000.00 or imprisonment for not
5 more than 6 months, or both.

6 Sec. 6. An individual or his or her representative may,
7 within 10 days after making a written request, inspect, request
8 correction of, or obtain a copy of a record of genetic informa-
9 tion about the individual. If a copy of a record is requested,
10 the individual or his or her representative may be charged the
11 actual cost of copying the record.

12 Sec. 7. This act applies only to genetic information that
13 can be identified as belonging to an individual or family. This
14 act does not affect any law, contract, or other arrangement that
15 determines a person's right to compensation for substances or
16 data derived from an individual's genetic information.

17 Sec. 8. (1) Subject to subsection (2), a person shall not
18 disclose, or be compelled to disclose by subpoena or any other
19 means, either of the following:

20 (a) The identity of an individual upon whom a genetic test
21 has been performed.

22 (b) Genetic information about an individual that permits
23 identification of the individual.

24 (2) The prohibitions described in subsection (1) do not
25 apply if 1 or more of the following conditions exist:

1 (a) The individual who is the subject of the genetic test or
2 who provides genetic information expressly consents in writing to
3 the disclosure.

4 (b) The disclosure is required to meet a purpose described
5 in section 4.

6 (c) A court having jurisdiction orders the disclosure.

7 (d) The disclosure is required to furnish genetic informa-
8 tion relating to a decedent for medical diagnosis of blood rela-
9 tives of the decedent.

10 (e) The disclosure is to an insurer, health care corpora-
11 tion, or health maintenance organization under contract to pay
12 all or a portion of the genetic test costs, and the disclosure is
13 limited to identification of the individual and the cost of
14 obtaining genetic information from, or providing a genetic test
15 to, the individual.

16 (3) A person who violates this section is guilty of a felony
17 punishable by a fine of \$5,000.00 or imprisonment for not more
18 than 1 year, or both.

19 Sec. 9. The requirements imposed under this act for acquir-
20 ing, retaining, or disclosing genetic information about an indi-
21 vidual apply to each acquisition, retention, or disclosure of
22 genetic information about the individual.

23 Sec. 10. A person who violates this act is liable for all
24 actual damages, or \$10,000.00, whichever is greater, including
25 damages for economic or noneconomic injury, established in a
26 civil action to have been proximately caused by the violation,
27 plus reasonable attorney fees and costs.