

1 H.370

2 Introduced by Representative Rachelson of Burlington

3 Referred to Committee on

4 Date:

5 Subject: Health; genetic information; privacy

6 Statement of purpose of bill as introduced: This bill proposes to identify a
7 DNA sample and the results of a DNA analysis performed on the sample as the
8 exclusive property of the person sampled or analyzed and to provide criminal
9 and civil penalties for unlawful DNA collection, analysis, retention, or
10 disclosure.

11 An act relating to genetic testing privacy and protection

12 It is hereby enacted by the General Assembly of the State of Vermont:

13 Sec. 1. 18 V.S.A. chapter 217 is amended to read:

14 CHAPTER 217. GENETIC TESTING

15 § 9331. DEFINITIONS

16 ~~For purposes of~~ As used in this chapter:

17 (1) "Commissioner" means the Commissioner of Financial Regulation.

18 (2) "DNA" means deoxyribonucleic acid and "RNA" means ribonucleic
19 acid.

20 (3) "Employee" has the same meaning as in 21 V.S.A. § 495d.

1 (4) “DNA analysis” means DNA or genetic typing and testing to
2 determine the presence of genetic characteristics in an individual, including
3 tests of nucleic acids or chromosomes to diagnose or identify a genetic
4 characteristic.

5 (5) “Employer” has the same meaning as in 21 V.S.A. § 495d.

6 ~~(5)~~(6) “Employment agency” has the same meaning as in 21 V.S.A.
7 § 495d.

8 ~~(6)~~(7) “Genetic information” means the results of genetic testing
9 contained in any report, interpretation, evaluation, or other record thereof.

10 ~~(7)~~(8)(A) “Genetic testing” means a test, examination, or analysis that is
11 diagnostic or predictive of a particular heritable disease or disorder and is of:

- 12 (i) a human chromosome or gene;
13 (ii) human DNA or RNA; or
14 (iii) a human genetically encoded protein.

15 (B) The test for human genetically encoded protein referred to in
16 subdivision (A)(iii) of this subdivision ~~(7)~~(8) shall be generally accepted in the
17 scientific and medical communities as being specifically determinative for the
18 presence or absence of a mutation, alteration, or deletion of a gene or
19 chromosome.

20 (C) For the purposes of sections 9332 and 9333 of this title, as they
21 apply to insurers, section 9334 of this title, and 8 V.S.A. § 4727, and

1 notwithstanding any language in this section to the contrary, “genetic testing”
2 does not include:

3 (i) a test, examination, or analysis ~~which~~ that reports on an
4 individual’s current condition unless such a test, examination, or analysis is
5 designed or intended to be specifically determinative for the presence or
6 absence of a mutation, alteration, or deletion of a gene or chromosome; or

7 (ii) a test, examination, or analysis of a human chromosome or
8 gene, of human DNA or RNA, or of a human genetically encoded protein that
9 is diagnostic or predictive of a particular heritable disease or disorder, if, in
10 accordance with generally accepted standards in the medical community, the
11 potential presence or absence of a mutation, alteration, or deletion of a gene or
12 chromosome has already manifested itself by causing a disease, disorder, or
13 medical condition or by symptoms highly predictive of the disease, disorder, or
14 medical condition.

15 ~~(8)~~(9) “Insurance” means a policy of insurance regulated under Title 8,
16 offered or issued in this State, including health, life, disability, and long-term
17 care insurance policies, hospital and medical service corporation service
18 contracts, and health maintenance organization benefit plans.

19 ~~(9)~~(10) “Labor organization” has the same meaning as in 21 V.S.A.
20 § 495d.

1 ~~(10)~~(11) “Licensing agency” means a unit of State government
2 authorized to grant, deny, renew, revoke, suspend, annul, withdraw, or amend
3 a professional license, certification, or registration.

4 § 9332. GENETIC TESTING; LIMITATIONS

5 (a) No person shall be required to undergo genetic testing, except as
6 provided in this chapter.

7 (b) A person may be required to undergo genetic testing in connection with
8 insurance subject to the limitations imposed under section 9334 of this title or
9 if otherwise required by law for the following reasons:

10 (1) to establish parentage;

11 (2) to determine the presence of metabolic disorders in a newborn by
12 testing conducted pursuant to newborn screening and protocols;

13 (3) in connection with a criminal investigation or prosecution;

14 (4) for remains identification by the chief medical examiner or designee;

15 (5) for purposes of the State DNA Data Bank, the State DNA Database,

16 and CODIS pursuant to 20 V.S.A. chapter 113, subchapter 4-; and

17 (6) for purposes of emergency medical treatment.

18 (c) Samples collected pursuant to subdivision (b)(1), (2), (3), or (4) of this
19 section or collected voluntarily pursuant to an agreement shall not be utilized
20 for any purpose in connection with the State DNA Data Bank, the State DNA

1 Database, and CODIS unless specifically authorized by 20 V.S.A. chapter 113,
2 subchapter 4.

3 (d) Except for the provisions of subsection (b) of this section, a DNA
4 sample and the results of a DNA analysis performed on the sample are the
5 exclusive property of the person sampled or analyzed and no genetic testing
6 shall be performed on any individual or body parts of any individual nor shall
7 any bodily materials be released for purposes of genetic testing without the
8 prior written authorization and informed consent of the individual to be tested
9 except for medical research where the identity of the subject is unknown or, if
10 the research shall be conducted with anonymized medical information where
11 individual identifiers are encrypted or encoded and the identity of the
12 individual is not disclosed, or if the identity of the individual is known, where
13 standards of protection are equal to those contained in regulations promulgated
14 by the federal Office for Protection from Research Risk (OPRR).

15 (e) Except for the provisions of subsection (b) of this section, any results of
16 genetic testing or the fact that an individual has requested genetic services or
17 undergone genetic testing shall be disclosed only pursuant to a written
18 authorization executed by the individual tested or by a person authorized by
19 law to act for the individual.

20 (f) Except for the provisions of subsection (b) of this section, at the time of
21 suggesting or requesting that an individual consent to genetic testing, the

1 person making the suggestion or request shall advise the individual subject of
2 the test that the results of the test:

3 (1) may become part of the individual's permanent medical record; and

4 (2) may be material to the ability of the individual to obtain certain
5 insurance benefits.

6 (g) A general authorization for the release of medical records or medical
7 information shall not be construed as the informed and written consent
8 required by this section. The Department of Health may adopt by rule a
9 uniform informed and written consent form to assist persons in meeting the
10 requirements of this section. A person using that uniform informed and written
11 consent form shall be exempt from civil or criminal liability for actions taken
12 under the consent form. A person may revoke or amend their informed and
13 written consent at any time.

14 § 9333. GENETIC TESTING; EMPLOYMENT; MEMBERSHIP IN A
15 LABOR ORGANIZATION; PROFESSIONAL LICENSURE

16 (a) No person shall, directly or indirectly, do any of the following as a
17 condition of, or to affect the terms, conditions, or privileges of employment, of
18 membership in a labor organization, or of professional licensure, certification,
19 or registration:

20 (1) use the fact that genetic counseling or testing services have been
21 requested or that genetic testing has been performed;

1 (2) the results of genetic testing of a member of the individual's family.

2 (b) A violation of this section shall be considered an unfair method of
3 competition or unfair or deceptive act or practice in the business of insurance
4 in violation of 8 V.S.A. § 4724.

5 (c) In addition to other remedies available under the law, a person who
6 violates this section shall be subject to the enforcement provisions available
7 under Title 8.

8 § 9335. PENALTIES; REMEDIES

9 (a) Any person who intentionally violates section 9333 or subsection
10 9334(a) of this chapter, or commits unlawful DNA collection, analysis,
11 retention, or disclosure shall be imprisoned not more than one year or fined not
12 more than \$10,000.00, or both.

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

18 (c) Any person aggrieved by a violation of this chapter may bring an action
19 for civil damages, including punitive damages, equitable relief, including
20 restraint of prohibited acts, restitution of wages or other benefits, and

1 reinstatement, costs, and reasonable attorney's fees, and other appropriate
2 relief.

3 Sec. 2. EFFECTIVE DATE

4 This act shall take effect on July 1, 2019.