
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

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AND SAMUELSON, APRIL 3, 2023

REFERRED TO COMMITTEE ON CONSUMER PROTECTION, TECHNOLOGY AND
UTILITIES, APRIL 3, 2023

AN ACT

1 Providing for privacy, transparency and compensation regarding
2 the disclosure of information collected by genetic material
3 testing entities.

4 The General Assembly of the Commonwealth of Pennsylvania
5 hereby enacts as follows:

6 Section 1. Short title.

7 This act shall be known and may be cited as the Genetic
8 Materials Privacy and Compensation Act.

9 Section 2. Definitions.

10 The following words and phrases when used in this act shall
11 have the meanings given to them in this section unless the
12 context clearly indicates otherwise:

13 "Genetic material." As follows:

14 (1) Deoxyribonucleic acid, including mitochondrial DNA,
15 complementary DNA and DNA derived from ribonucleic acid.

16 (2) The term includes a gene, chromosome or alteration
17 of a gene or chromosome that may be tested to determine the

1 existence or risk of a disease, disorder, trait, propensity,
2 syndrome or information identifying an individual or a blood
3 relative.

4 (3) The term does not include family history or a
5 genetically transmitted characteristic whose existence or
6 identity is determined through means other than a genetic
7 test.

8 "Genetic material collection." Information collected, or
9 planned to be collected, by a genetic material testing entity
10 about the content accessed, personal identifiers, reports or
11 knowledge derived from testing and any other reports or
12 statistics combined with the information or data.

13 "Genetic material testing." As follows:

14 (1) DNA or genetic typing and testing to determine the
15 presence or absence of genetic characteristics in an
16 individual.

17 (2) The term includes a test of nucleic acids or
18 chromosomes in order to diagnose or identify a genetic
19 characteristic.

20 (3) The term does not include:

21 (i) A routine physical measurement.

22 (ii) A test for drugs, alcohol, cholesterol or human
23 immunodeficiency virus.

24 (iii) A chemical, blood or urine analysis.

25 (iv) Any other diagnostic test that is widely
26 accepted and in use in clinical practice.

27 "Genetic material testing entity." An entity collecting,
28 testing or otherwise analyzing the genetic material of
29 individuals, including:

30 (1) A medical facility.

1 (2) An entity that provides genealogy services.

2 (3) A law enforcement official.

3 "Prominently disclose." To communicate in a manner that is
4 difficult to miss and easily understandable by ordinary
5 individuals, including the following:

6 (1) A visual disclosure that, by its size, contrast,
7 location, length, appearance and other characteristics,
8 stands out from accompanying text or other visual elements so
9 that it is easily noticed, read and understood.

10 (2) An audible disclosure, including by telephone or
11 streaming video, that is delivered in a volume, speed and
12 cadence sufficient for ordinary individuals to easily hear
13 and understand.

14 (3) An interactive electronic medium, such as in
15 connection with an update to device firmware, the disclosure
16 of which is unavoidable.

17 (4) A disclosure that uses diction and syntax
18 understandable to ordinary individuals and appears in each
19 language in which the triggering representation appears.

20 (5) A disclosure that complies with the requirements in
21 each medium through which it is received, including all
22 electronic devices and face-to-face communications.

23 (6) A disclosure that is not contradicted, mitigated by
24 or inconsistent with anything else in the communication.

25 When the communication targets a specific audience, such as
26 children, the elderly or the terminally ill, the term "ordinary
27 individuals" includes reasonable members of that group.

28 "Third party." An entity that gathers or otherwise has
29 access to an individual's genetic material whether obtained for
30 the entity's purposes or accessed from another entity.

1 Section 3. Disclosure requirements.

2 (a) Prohibition.--In addition to other requirements imposed
3 by law, a genetic material testing entity, directly or through a
4 corporation, subsidiary, division, website or other device or
5 affiliate, may not misrepresent, expressly or by implication:

6 (1) The extent to which data is collected, used or
7 maintained or methods for protecting the privacy,
8 confidentiality or security of genetic material.

9 (2) The purpose of the collection, use or disclosure of
10 genetic material.

11 (b) Notice and consent.--

12 (1) A genetic material testing entity or third party,
13 directly or through a corporation, subsidiary, division,
14 website or other device or affiliate, in connection with the
15 collection of genetic material of an individual, shall:

16 (i) Prior to collection of the genetic material
17 undertaken after the effective date of this section,
18 prominently disclose to the individual, separate and
19 apart from a privacy policy, terms of use page or other
20 similar documents, the following:

21 (A) The type of genetic material that will be
22 collected and used.

23 (B) The type of genetic material that will be
24 shared with a third party.

25 (C) The identity of the third party.

26 (D) The purpose for any genetic testing entity
27 sharing of the data collected.

28 (E) A data sharing agreement between the genetic
29 testing entity or third party and a Federal, State or
30 local law enforcement agency or other government

1 agency.

2 (ii) Obtain the individual's affirmative express
3 consent to the genetic material collection as follows:

4 (A) At the time the disclosure under
5 subparagraph (i) is made.

6 (B) Upon a material change to the terms
7 disclosed under subparagraph (i).

8 (iii) Provide instruction, if the individual's
9 affirmative express consent is sought under subparagraph
10 (ii), for how the individual may revoke consent to the
11 genetic material collection and sharing.

12 (iv) Obtain the individual's affirmative express
13 consent to continued genetic material collection or
14 sharing.

15 (2) A genetic testing entity or third party, directly or
16 through a corporation, subsidiary, division, website or other
17 device or affiliate, may not collect the genetic material of
18 an individual who does not provide affirmative express
19 consent under paragraph (1)(ii).

20 (3) A genetic material testing entity or third party
21 collecting or accessing the genetic material of an individual
22 shall not provide information on the genetic material to law
23 enforcement without a warrant or the explicit, affirmative
24 permission of the individual providing the genetic material.

25 Section 4. Compensation.

26 (a) Prohibition.--A genetic material testing entity or third
27 party collecting or accessing the genetic material of an
28 individual is prohibited from:

29 (1) selling or donating information about an
30 individual's genetic material without getting express

1 authorization from the individual or, in the case the
2 individual is deceased, the next of kin; and

3 (2) providing fair and adequate compensation at a rate
4 of not less than 90% of the amount received in compensation
5 for the sale of the individual's genetic material.

6 (b) Nonapplicability.--Subsection (a)(2) does not apply if
7 an individual or, in the case the individual is deceased, the
8 next of kin, makes a voluntary and direct genetic material
9 donation of the individual's genetic material for medical
10 treatment or medical or scientific study.

11 Section 5. Genetic materials database requests.

12 (a) Insurance companies.--An insurance company may not
13 request genetic material or related data of an insured or an
14 individual applying for insurance from a company or entity
15 maintaining a genetic database.

16 (b) Employers.--An employer may not request genetic material
17 or related data of an employee or a prospective employee from a
18 company or entity maintaining a genetic database.

19 Section 6. Data deletion requirements.

20 (a) General rule.--Within 120 days of the effective date of
21 this section, a genetic material testing entity or third party,
22 in connection with genetic material collection for a product or
23 service, and any person or entity in active concert or
24 participation, directly or through a corporation, subsidiary,
25 division, website or other device or affiliate, shall destroy
26 genetic material collected prior to the effective date of this
27 section, except:

28 (1) If the genetic material collected was requested by a
29 government agency or required by law, regulation or court
30 order, including without limitation as required by rules

1 applicable to the safeguarding of evidence in pending
2 litigation.

3 (2) If the individual associated with the genetic
4 material collected has expressly consented to the collection,
5 use or disclosure as provided under section 3(b).

6 (b) Individual request.--After the effective date of this
7 section, a genetic material testing entity or third party in
8 connection with genetic material collection, and any person or
9 entity in active concert or participation with a genetic
10 material testing entity or third party, directly or through a
11 corporation, subsidiary, division, website or other device or
12 affiliate, shall destroy the genetic material within 30 days of
13 the individual requesting that the genetic material be
14 destroyed.

15 Section 7. Mandated genetic materials privacy program.

16 (a) Privacy program.--A genetic material testing entity or
17 third party, directly or through a corporation, subsidiary,
18 division, website or affiliate, shall establish, implement and
19 maintain a comprehensive privacy program that is reasonably
20 designed to:

21 (1) Address privacy risks related to the development and
22 management of new and existing products and services for
23 individuals.

24 (2) Protect the privacy and confidentiality of genetic
25 material collected directly or indirectly by a genetic
26 material testing entity or third party, directly or through a
27 corporation, subsidiary, division, website or other device or
28 affiliate.

29 (b) Requirements.--A privacy program, the content and
30 implementation of which shall be documented in writing, shall

1 contain controls and procedures appropriate to the size and
2 complexity of the party collecting the genetic material, the
3 nature and scope of the party's activities and the sensitivity
4 of the genetic material, including:

5 (1) The designation of an employee or employees to
6 coordinate and be responsible for the privacy program.

7 (2) The identification of reasonably foreseeable risks,
8 both internal and external, that could result in the
9 unauthorized collection, use or disclosure by the party
10 collecting the genetic material or its agents and an
11 assessment of the sufficiency of any safeguards in place to
12 control these risks. At a minimum, the risk assessment shall
13 include consideration of risks in each area of relevant
14 operation, including:

15 (i) Employee training and management, including
16 training on the requirements of this act.

17 (ii) Product design, development and research.

18 (3) The design and implementation of reasonable controls
19 and procedures to address risks and regular testing or
20 monitoring of the effectiveness of those controls and
21 procedures.

22 (4) The development and use of reasonable steps to
23 select and retain Internet service providers capable of
24 appropriately protecting the privacy of information they
25 receive from the genetic material testing entity or third
26 party or its agents and requiring the Internet service
27 providers, by contract, to implement and maintain appropriate
28 privacy protections for genetic material.

29 (5) The evaluation and adjustment of the genetic
30 material testing entity's or third party's privacy program in

1 light of the results of the testing and monitoring required
2 under paragraph (3), a change to the genetic material testing
3 entity or third party operations or business arrangements or
4 other circumstance that the manufacturer or third party or
5 its agents know or have reason to know may have an impact on
6 the effectiveness of the privacy program.

7 Section 8. Ownership.

8 Individuals shall have inherent ownership rights for their
9 genetic material and a privacy interest in it, even when
10 voluntarily providing their genetic material to a for-profit
11 company.

12 Section 9. Violations.

13 Conduct that is unlawful or otherwise prohibited under this
14 act shall constitute an "unfair method of competition" and
15 "unfair or deceptive act or practice" under section 2 of the act
16 of December 17, 1968 (P.L.1224, No.387), known as the Unfair
17 Trade Practices and Consumer Protection Law, and shall be
18 subject to enforcement and the remedies as provided in that act.

19 Section 10. Remedies available to individuals.

20 Nothing in this act shall be construed to limit the remedies
21 available to individuals, the Attorney General or a district
22 attorney under the act of December 17, 1968 (P.L.1224, No.387),
23 known as the Unfair Trade Practices and Consumer Protection Law,
24 or other Federal or State law.

25 Section 11. Effective date.

26 This act shall take effect in 120 days.