
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 2283 Session of
2022

INTRODUCED BY KINKEAD, HILL-EVANS, SANCHEZ, N. NELSON, ZABEL,
SCHLOSSBERG, KINSEY, MADDEN, BURGOS, DeLUCA, ISAACSON,
BRADFORD, ROZZI, CIRESI, DELLOSO, STURLA, DIAMOND AND
SHUSTERMAN, JANUARY 26, 2022

REFERRED TO COMMITTEE ON CONSUMER AFFAIRS, JANUARY 26, 2022

AN ACT

1 Providing for privacy, transparency and compensation regarding
2 the disclosure of information collected by genetic material
3 testing entities; and providing for powers and duties of the
4 Office of Attorney General.

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

7 Section 1. Short title.

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

10 Section 2. Definitions.

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

14 "Data collection." Information collected, or planned to be
15 collected, by a genetic material testing entity about the
16 content accessed, personal identifiers, reports or knowledge
17 derived from testing and any other reports or statistics
18 combined with the information or data.

1 "Genetic material." Deoxyribonucleic acid, including
2 mitochondrial DNA, complementary DNA, and DNA derived from
3 ribonucleic acid, including a gene, chromosome or alteration of
4 a gene or chromosome that may be tested to determine the
5 existence or risk of a disease, disorder, trait, propensity,
6 syndrome or information identifying an individual or a blood
7 relative. The term does not include family history or a
8 genetically transmitted characteristic whose existence or
9 identity is determined through means other than a genetic test.

10 "Genetic material testing." DNA or genetic typing and
11 testing to determine the presence or absence of genetic
12 characteristics in an individual, including a test of nucleic
13 acids or chromosomes in order to diagnose or identify a genetic
14 characteristic. The term does not include a routine physical
15 measurement; a test for drugs, alcohol, cholesterol, human
16 immunodeficiency virus; a chemical, blood, or urine analysis; or
17 other diagnostic test that is widely accepted and in use in
18 clinical practice.

19 "Genetic material testing entity." An entity collecting,
20 testing or otherwise analyzing the genetic material of
21 individuals, including:

- 22 (1) A medical facility.
- 23 (2) An entity that provides genealogy services.
- 24 (3) A law enforcement official.

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

- 28 (1) A visual disclosure that, by its size, contrast,
29 location, length, appearance and other characteristics,
30 stands out from accompanying text or other visual elements so

1 that it is easily noticed, read and understood.

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

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

9 (4) A disclosure that uses diction and syntax
10 understandable to ordinary individuals and appears in each
11 language in which the triggering representation appears.

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

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

17 When the communication targets a specific audience, such as
18 children, the elderly or the terminally ill, the term
19 "ordinary individuals" includes reasonable members of that
20 group.

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

24 Section 3. Disclosure requirements.

25 (a) General rule.--In addition to other requirements imposed
26 by law, a genetic material testing entity, directly or through a
27 corporation, subsidiary, division, website or other device or
28 affiliate, may not misrepresent, expressly or by implication:

29 (1) The extent to which data is collected, used or
30 maintained or methods for protecting the privacy,

1 confidentiality or security of genetic material.

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

4 (b) Notice and consent.--

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

9 (i) Prior to collection of the genetic material
10 undertaken after the effective date of this section,
11 prominently disclose to the individual, separate and
12 apart from a privacy policy, terms of use page or other
13 similar documents, the following:

14 (A) The type of genetic material that will be
15 collected and used.

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

18 (C) The identity of the third party.

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

21 (E) A data sharing agreement between the genetic
22 testing entity or third party and a Federal, State or
23 local law enforcement agency or other government
24 agency.

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

27 (A) At the time the disclosure under
28 subparagraph (i) is made.

29 (B) Upon a material change to the terms
30 disclosed under subparagraph (i).

1 (iii) Provide instruction, if the individual's
2 affirmative express consent is sought under subparagraph
3 (ii), for how the individual may revoke consent to the
4 genetic material collection and sharing.

5 (iv) Obtain the individual's affirmative express
6 consent to continued genetic material collection or
7 sharing.

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

13 (3) A genetic material testing entity or third-party
14 collecting or accessing the genetic material of an individual
15 shall not provide information on the genetic material to law
16 enforcement without a warrant or the explicit, affirmative
17 permission of the individual providing the genetic material.

18 Section 4. Compensation.

19 (a) General rule.--A genetic material testing entity or
20 third party collecting or accessing the genetic material of an
21 individual is prohibited from:

22 (1) selling or donating information about an
23 individual's genetic material without getting express
24 authorization from the individual or, in the case the
25 individual is deceased, the next of kin; and

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

29 (b) Nonapplicability.--Subsection (a)(2) does not apply if
30 an individual or, in the case the individual is deceased, the

1 next of kin, makes a voluntary and direct genetic material
2 donation of the individual's genetic material for medical
3 treatment or medical or scientific study.

4 Section. 5. Genetic materials database requests.

5 (a) Insurance companies.--An insurance company may not
6 request genetic material or related data of an insured or an
7 individual applying for insurance from a company or entity
8 maintaining a genetic database.

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

12 Section 6. Data deletion requirements.

13 (a) General rule.--Within 120 days of the effective date of
14 this section, a genetic material testing entity or third party,
15 in connection with genetic material collection for a product or
16 service, and any person or entity in active concert or
17 participation, directly or through a corporation, subsidiary,
18 division, website or other device or affiliate, shall destroy
19 genetic material collected prior to the effective date of this
20 section, except:

21 (1) If the genetic material collected was requested by a
22 government agency or required by law, regulation or court
23 order, including without limitation as required by rules
24 applicable to the safeguarding of evidence in pending
25 litigation.

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

29 (b) Individual request.--After the effective date of this
30 section, a genetic material testing entity or third party in

1 connection with genetic material collection, and any person or
2 entity in active concert or participation with a genetic
3 material testing entity or third party, directly or through a
4 corporation, subsidiary, division, website or other device or
5 affiliate, shall destroy the genetic material within 30 days of
6 the individual requesting that the genetic material be
7 destroyed.

8 Section 7. Mandated genetic materials privacy program.

9 (a) General rule.--A genetic material testing entity or
10 third party, directly or through a corporation, subsidiary,
11 division, website or affiliate, shall establish, implement and
12 maintain a comprehensive privacy program that is reasonably
13 designed to:

14 (1) Address privacy risks related to the development and
15 management of new and existing products and services for
16 individuals.

17 (2) Protect the privacy and confidentiality of genetic
18 material collected directly or indirectly by a genetic
19 material testing entity or third party, directly or through a
20 corporation, subsidiary, division, website or other device or
21 affiliate.

22 (b) Requirements.--A privacy program, the content and
23 implementation of which shall be documented in writing, shall
24 contain controls and procedures appropriate to the size and
25 complexity of the party collecting the genetic material, the
26 nature and scope of the party's activities and the sensitivity
27 of the genetic material, including:

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

30 (2) The identification of reasonably foreseeable risks,

1 both internal and external, that could result in the
2 unauthorized collection, use or disclosure by the party
3 collecting the genetic material or its agents and an
4 assessment of the sufficiency of any safeguards in place to
5 control these risks. At a minimum, the risk assessment shall
6 include consideration of risks in each area of relevant
7 operation, including:

8 (i) Employee training and management including
9 training on the requirements of this act.

10 (ii) Product design, development and research.

11 (3) The design and implementation of reasonable controls
12 and procedures to address risks and regular testing or
13 monitoring of the effectiveness of those controls and
14 procedures.

15 (4) The development and use of reasonable steps to
16 select and retain Internet service providers capable of
17 appropriately protecting the privacy of information they
18 receive from the genetic material testing entity or third
19 party or its agents and requiring the Internet service
20 providers, by contract, to implement and maintain appropriate
21 privacy protections for genetic material.

22 (5) The evaluation and adjustment of the genetic
23 material testing entity or third party's privacy program in
24 light of the results of the testing and monitoring required
25 under paragraph (3), a change to the genetic material testing
26 entity or third party operations or business arrangements or
27 other circumstance that the manufacturer or third party or
28 its agents know or have reason to know may have an impact on
29 the effectiveness of the privacy program.

30 Section 8. Ownership.

1 Individuals shall have inherent ownership rights for their
2 genetic material and a privacy interest in it, even when
3 voluntarily providing their genetic material to a for-profit
4 company.

5 Section 9. Violations.

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

12 Section 10. Remedies available to individuals.

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

18 Section 11. Effective date.

19 This act shall take effect in 120 days.