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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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HOUSE BILL

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SAMUELSON, APRIL 9, 2025

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REFERRED TO COMMITTEE ON CONSUMER PROTECTION, TECHNOLOGY AND  
UTILITIES, APRIL 9, 2025

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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 agency.

3 "Prominently disclose." As follows:

4 (1) To communicate in a manner that is difficult to miss  
5 and easily understandable by ordinary individuals, including  
6 the following:

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

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

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

19 (iv) A disclosure that uses diction and syntax  
20 understandable to ordinary individuals and appears in  
21 each language in which the triggering representation  
22 appears.

23 (v) A disclosure that complies with the requirements  
24 in each medium through which it is received, including  
25 all electronic devices and face-to-face communications.

26 (vi) A disclosure that is not contradicted,  
27 mitigated by or inconsistent with anything else in the  
28 communication.

29 (2) When the communication targets a specific audience,  
30 such as children, the elderly or the terminally ill, the term

1 "ordinary individuals" includes reasonable members of that  
2 group.

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

6 Section 3. Disclosure requirements.

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

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

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

16 (b) Notice and consent.--

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

21 (i) Prior to collection of the genetic material  
22 undertaken after the effective date of this section,  
23 prominently disclose to the individual, separate and  
24 apart from a privacy policy, terms of use page or other  
25 similar documents, the following:

26 (A) The type of genetic material that will be  
27 collected and used.

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

30 (C) The identity of the third party.

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

3 (E) A data-sharing agreement between the genetic  
4 testing entity or third party and a Federal, State or  
5 local law enforcement agency or other government  
6 agency.

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

9 (A) At the time the disclosure under  
10 subparagraph (i) is made.

11 (B) Upon a material change to the terms  
12 disclosed under subparagraph (i).

13 (iii) Provide instruction, if the individual's  
14 affirmative express consent is sought under subparagraph  
15 (ii), for how the individual may revoke consent to the  
16 genetic material collection and sharing.

17 (iv) Obtain the individual's affirmative express  
18 consent to continued genetic material collection or  
19 sharing.

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

25 (3) A genetic material testing entity or third party  
26 collecting or accessing the genetic material of an individual  
27 shall not provide information on the genetic material to law  
28 enforcement without a warrant or the explicit, affirmative  
29 permission of the individual providing the genetic material.

30 Section 4. Compensation.

1 (a) Prohibition.--A genetic material testing entity or third  
2 party collecting or accessing the genetic material of an  
3 individual is prohibited from selling or donating information  
4 about an individual's genetic material without:

5 (1) getting express authorization from the individual  
6 or, in the case that the individual is deceased, the next of  
7 kin; and

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

11 (b) Nonapplicability.--Subsection (a)(2) does not apply if  
12 an individual or, in the case that the individual is deceased,  
13 the next of kin, makes a voluntary and direct genetic material  
14 donation of the individual's genetic material for medical  
15 treatment or medical or scientific study.

16 Section 5. Genetic materials database requests.

17 (a) Insurance companies.--An insurance company may not  
18 request genetic material or related data of an insured or an  
19 individual applying for insurance from a company or entity  
20 maintaining a genetic database.

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

24 Section 6. Data deletion requirements.

25 (a) Destruction of genetic material.--Within 120 days of the  
26 effective date of this section, a genetic material testing  
27 entity or third party, in connection with genetic material  
28 collection for a product or service, and any person or entity in  
29 active concert or participation, directly or through a  
30 corporation, subsidiary, division, website or other device or

1 affiliate, shall destroy genetic material collected prior to the  
2 effective date of this section, except:

3 (1) If the genetic material collected was requested by a  
4 government agency or required by law, regulation or court  
5 order, including rules applicable to the safeguarding of  
6 evidence in pending litigation.

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

10 (b) Individual request.--After the effective date of this  
11 section, a genetic material testing entity or third party in  
12 connection with genetic material collection, and any person or  
13 entity in active concert or participation with a genetic  
14 material testing entity or third party, directly or through a  
15 corporation, subsidiary, division, website or other device or  
16 affiliate, shall destroy an individual's genetic material within  
17 30 days of the individual requesting that the genetic material  
18 be destroyed.

19 Section 7. Mandated genetic materials privacy program.

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

25 (1) Address privacy risks related to the development and  
26 management of new and existing products and services for  
27 individuals.

28 (2) Protect the privacy and confidentiality of genetic  
29 material collected directly or indirectly by a genetic  
30 material testing entity or third party, directly or through a

1 corporation, subsidiary, division, website or other device or  
2 affiliate.

3 (b) Requirements.--A privacy program, the content and  
4 implementation of which shall be documented in writing, shall  
5 contain controls and procedures appropriate to the size and  
6 complexity of the party collecting the genetic material, the  
7 nature and scope of the party's activities and the sensitivity  
8 of the genetic material, including:

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

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

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

22 (ii) Product design, development and research.

23 (3) The design and implementation of reasonable controls  
24 and procedures to address risks and regular testing or  
25 monitoring of the effectiveness of those controls and  
26 procedures.

27 (4) The development and use of reasonable steps to  
28 select and retain Internet service providers capable of  
29 appropriately protecting the privacy of information that the  
30 Internet service providers receive from the genetic material

1 testing entity or third party or agents of the genetic  
2 material testing entity or third party and requiring the  
3 Internet service providers, by contract, to implement and  
4 maintain appropriate privacy protections for genetic  
5 material.

6 (5) The evaluation and adjustment of the genetic  
7 material testing entity's or third party's privacy program in  
8 light of the results of the testing and monitoring required  
9 under paragraph (3), a change to the genetic material testing  
10 entity's or third party's operations or business arrangements  
11 or other circumstance that the manufacturer or third party or  
12 agents of the manufacturer or third party know or have reason  
13 to know may have an impact on the effectiveness of the  
14 privacy program.

15 Section 8. Ownership.

16 Individuals shall have inherent ownership rights for their  
17 genetic material and a privacy interest in it, even when  
18 voluntarily providing their genetic material to a for-profit  
19 company.

20 Section 9. Violations.

21 Conduct that is unlawful or otherwise prohibited under this  
22 act shall constitute an unfair method of competition and unfair  
23 or deceptive act or practice as those terms are defined under  
24 section 2 of the act of December 17, 1968 (P.L.1224, No.387),  
25 known as the Unfair Trade Practices and Consumer Protection Law,  
26 and shall be subject to enforcement and remedies as provided in  
27 that act.

28 Section 10. Remedies available to individuals.

29 Nothing in this act shall be construed to limit the remedies  
30 available to individuals, the Attorney General or a district

1 attorney under the act of December 17, 1968 (P.L.1224, No.387),  
2 known as the Unfair Trade Practices and Consumer Protection Law,  
3 or other Federal or State law.

4 Section 11. Effective date.

5 This act shall take effect in 120 days.