

LEGISLATURE OF NEBRASKA  
ONE HUNDRED EIGHTH LEGISLATURE  
FIRST SESSION

**LEGISLATIVE BILL 308**

Introduced by Bostar, 29.

Read first time January 11, 2023

Committee: Banking, Commerce and Insurance

1 A BILL FOR AN ACT relating to public health and welfare; to adopt the

2 Genetic Information Privacy Act.

3 Be it enacted by the people of the State of Nebraska,

1           Section 1. Sections 1 through 4 shall be known and may be cited as  
2 the Genetic Information Privacy Act.

3           Sec. 2. For purposes of the Genetic Information Privacy Act:

4           (1) Biological sample means any material part of a human being,  
5 discharge therefrom, or derivative thereof, such as tissue, blood, urine,  
6 or saliva, known to contain DNA.

7           (2) Consumer means an individual who is a resident of Nebraska.

8           (3) Direct-to-consumer genetic testing company or company means an  
9 entity that (a) offers consumer genetic testing products or services  
10 directly to a consumer, or (b) collects, uses, or analyzes genetic data  
11 that resulted from a direct-to-consumer genetic testing product or  
12 service and was provided to the company by a consumer. Direct-to-consumer  
13 genetic testing company does not include any entity that is solely  
14 engaged in collecting, using, or analyzing genetic data or biological  
15 samples in the context of research, as defined in 45 C.F.R. 164.501,  
16 conducted in accordance with the Federal Policy for the Protection of  
17 Human Subjects, 45 C.F.R. part 46, the Good Clinical Practice Guideline  
18 issued by the International Council for Harmonisation, or the United  
19 States Food and Drug Administration Policy for the Protection of Human  
20 Subjects under 21 C.F.R. parts 50 and 56.

21           (4) DNA means deoxyribonucleic acid.

22           (5) Express consent means a consumer's affirmative response to a  
23 clear, meaningful, and prominent notice regarding the collection, use, or  
24 disclosure of genetic data for a specific purpose.

25           (6)(a) Genetic data means any data, regardless of its format, that  
26 concerns a consumer's genetic characteristics. Genetic data includes, but  
27 is not limited to: (i) Raw sequence data that results from sequencing of  
28 a consumer's complete extracted DNA or a portion of the extracted DNA;  
29 (ii) genotypic and phenotypic information that results from analyzing the  
30 raw sequence data; and (iii) self-reported health information that a  
31 consumer submits to a company regarding the consumer's health conditions

1 and that is used for scientific research or product development and  
2 analyzed in connection with the consumer's raw sequence data.

3 (b) Genetic data does not include de-identified data. For purposes  
4 of this subdivision, de-identified data means data that cannot reasonably  
5 be used to infer information about, or otherwise be linked to, an  
6 identifiable consumer, and that is subject to: (i) Administrative and  
7 technical measures to ensure that the data cannot be associated with an  
8 identifiable consumer; (ii) public commitment by the company to maintain  
9 and use data in de-identified form and not attempt to reidentify data;  
10 and (iii) legally enforceable contractual obligations that prohibit any  
11 recipients of the data from attempting to reidentify the data.

12 (7) Genetic testing means any laboratory test of a consumer's  
13 complete DNA, regions of DNA, chromosomes, genes, or gene products to  
14 determine the presence of genetic characteristics of a consumer.

15 (8) Person means an individual, partnership, corporation,  
16 association, business, business trust, or legal representative of an  
17 organization.

18 Sec. 3. (1) In order to safeguard the privacy, confidentiality,  
19 security, and integrity of a consumer's genetic data, a direct-to-  
20 consumer genetic testing company shall:

21 (a) Provide clear and complete information regarding the company's  
22 policies and procedures for collection, use, or disclosure of genetic  
23 data by making available to a consumer: (i) A high-level privacy policy  
24 overview that includes basic information about the company's collection,  
25 use, or disclosure of genetic data; and (ii) a prominent, publicly  
26 available privacy notice that includes, at a minimum, information about  
27 the company's data collection, consent, use, access, disclosure,  
28 transfer, security, and retention and deletion practices;

29 (b) Obtain a consumer's consent for collection, use, or disclosure  
30 of the consumer's genetic data, including:

31 (i) Initial express consent that clearly states the uses for which

1 the genetic data collected through the genetic testing product or service  
2 is intended, specifies the parties who have access to test results, and  
3 the means by which such genetic data may be shared;

4 (ii) Separate express consent for transferring or disclosing the  
5 consumer's genetic data to any person other than the company's vendors  
6 and service providers, or for using genetic data for purposes not stated  
7 in subdivision (b)(i) of this section and inherent contextual uses;

8 (iii) Separate express consent for the retention of any biological  
9 sample provided by the consumer following completion of the initial  
10 testing service requested by the consumer;

11 (iv) Informed consent in compliance with the Federal Policy for the  
12 Protection of Human Research Subjects, as described in 45 C.F.R. part 46,  
13 for transfer or disclosure of the consumer's genetic data to third-party  
14 persons for research purposes or research conducted under the control of  
15 the company for the purpose of publication or generalizable knowledge;  
16 and

17 (v) Express consent for marketing to a consumer based on the  
18 consumer's genetic data or for marketing by a third-party person to a  
19 consumer based on the order or purchase by a consumer of a genetic  
20 testing product or service. For purposes of this subdivision, marketing  
21 does not include the provision of customized content or offers on  
22 websites or through applications or services provided by the direct-to-  
23 consumer genetic testing company having the first-party relationship to  
24 the consumer;

25 (c) Require valid legal process before disclosing genetic data to  
26 any government agency, including law enforcement, without the consumer's  
27 express written consent;

28 (d) Develop, implement, and maintain a comprehensive security  
29 program to protect a consumer's genetic data from unauthorized access,  
30 use, or disclosure; and

31 (e) Provide a process for a consumer to (i) access the consumer's

1 genetic data, (ii) delete the consumer's account and genetic data, and  
2 (iii) request and obtain written documentation verifying the destruction  
3 of the consumer's biological sample.

4 (2) A direct-to-consumer genetic testing company shall not disclose  
5 a consumer's genetic data to any entity offering health insurance, life  
6 insurance, long-term care insurance, or to any employer of the consumer  
7 without the consumer's written consent.

8 (3) The Attorney General may bring an action on behalf of a consumer  
9 to enforce the provisions of the Genetic Information Privacy Act. A  
10 violation of the act is subject to a civil penalty of two thousand five  
11 hundred dollars for each violation, in addition to actual damages  
12 incurred by the consumer, and costs and reasonable attorney's fees  
13 incurred by the Attorney General.

14 Sec. 4. (1) The Genetic Information Privacy Act does not apply to  
15 protected health information collected by a covered entity or business  
16 associate as those terms are defined in 45 C.F.R. parts 160 and 164.

17 (2) The disclosure of genetic data pursuant to the Genetic  
18 Information Privacy Act shall comply with all state and federal laws for  
19 the protection of privacy and security. The act shall not apply to  
20 protected health information collected by a covered entity or business  
21 associate governed by the privacy, security, and breach notification  
22 rules issued by the federal Department of Health and Human Services, 45  
23 C.F.R. parts 160 and 164, established pursuant to the Health Insurance  
24 Portability and Accountability Act of 1996, Public Law 104-191, and the  
25 Health Information Technology for Economic and Clinical Health Act,  
26 enacted as part of the American Recovery and Reinvestment Act of 2009,  
27 Public Law 111-5.