HOUSE BILL NO. HB0086

Genetic data privacy-amendments.

Sponsored by: Select Committee on Blockchain, Financial Technology and Digital Innovation Technology

A BILL

for

1 AN ACT relating to genetic data privacy; prohibiting the

2 collection, retention and disclosure of genetic data as

3 specified; providing exceptions; providing for a civil

4 cause of action by the attorney general as specified;

5 providing definitions; specifying applicability; and

6 providing for an effective date.

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8 Be It Enacted by the Legislature of the State of Wyoming:

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10 **Section 1.** W.S. 35-32-105 is created to read:

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12 35-32-105. General provisions; limitations.

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- 1 (a) The provisions of this chapter applicable to
- 2 direct to consumer genetic testing companies shall not be
- 3 waived.

- 5 (b) The disclosure of genetic data pursuant to this
- 6 chapter shall comply with all state and federal laws for
- 7 the protection of privacy and security. This chapter shall
- 8 not apply to protected health information that is collected
- 9 by a covered entity or business associate governed by the
- 10 privacy, security and breach notification rules issued by
- 11 the United States Department of Health and Human Services
- 12 (Parts Regulations) 160 and 164 of Title 45 of the Code of
- 13 Federal Services (Parts Regulations) established pursuant
- 14 to the federal Health Insurance Portability and
- 15 Accountability Act of 1996 (P.L. 104-191) and the federal
- 16 Health Information Technology for Economic and Clinical
- 17 Health Act (P.L. 111-5).

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- 19 **Section 2.** W.S. 35-32-101(a)(intro), (iii), (v),
- 20 (vi)(A), (B) and by creating new paragraphs (vii) through
- 21 (xi), 35-32-102(a), (b)(intro), (xi) and by creating new
- 22 subsections (c) and (d), 35-32-103 and 35-32-104(b) and by

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23 creating a new subsection (c) are amended to read:

1 2 CHAPTER 32 3 GENETIC INFORMATION DATA PRIVACY 4 35-32-101. Definitions. 5 6 (a) As used in this chapter unless otherwise defined: 7 8 9 (iii) "Genetic <u>analysis</u> <u>testing</u>" means <u>a any</u> 10 laboratory test of an individual's complete DNA, gene products or regions of DNA, chromosomes to determine the 11 presence or absence of or genes to determine the presence 12 13 of genetic characteristics in of an individual or family; 14 (v) "Genetic information" means information 15 16 about the data" means any data, regardless of its format, 17 that concerns an individual's genetic characteristics. of an individual or members of an individual's family that are 18 19 the results of genetic analysis; Genetic data includes: 20 21 (A) Raw sequence data that result from sequencing of an individual's complete extracted or a 22

portion of the extracted DNA;

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2	(B) Genotypic and phenotypic information
3	that results from analyzing the raw sequence data,
4	including any familial inferences therefrom; and
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6	(C) Self reported health information that
7	an individual submits to a company regarding the
8	individual's health conditions and that is used for
9	scientific research or product development and analyzed in
10	connection with the individual's raw sequence data.
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12	(vi) "Informed consent" means the signing of a
13	consent form or forms in writing or by electronic signature
14	as defined in W.S. 40-21-102(a)(viii) by an individual or
15	an individual's authorized representative which includes a
16	description of:
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18	(A) Any genetic analysis <u>testing</u> to be
19	performed and how the genetic <u>analysis</u> <u>testing</u> or resulting
20	genetic information data will be used;
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22	(B) How any genetic <u>information</u> data will
23	be retained or disclosed;

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2	(vii) "Biological sample" means any material
3	part of a human, discharge therefrom or derivative thereof
4	known to contain deoxyribonucleic acid (DNA), such as
5	tissue, blood, urine or saliva;
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7	(viii) "Consumer" means a natural person who is
8	a resident of the state of Wyoming;
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10	(ix) "Deidentified data" means data that cannot
11	be used to infer information about or otherwise be linked
12	to an identifiable individual, and that is subject to:
13	
14	(A) Administrative and technical measures
15	to ensure that the data cannot be associated with a
16	particular individual;
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18	(B) Public commitment by the company to
19	maintain and use data in deidentified form and not attempt
20	to reidentify data; and
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1	(C) Legally enforceable contractual							
2	obligations that prohibit any recipient of the data from							
3	attempting to reidentify the data.							
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5	(x) "Direct to consumer genetic testing company"							
6	or "company" means any person that offers consumer genetic							
7	testing products or services directly to consumers or who							
8	collects, uses or analyzes genetic data provided by a							
9	consumer;							
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11	(xi) "Express consent" means a consumer's							
12	affirmative response to a clear, meaningful and prominent							
13	notice regarding the collection, use or disclosure of the							
14	consumer's genetic data for a specific purpose.							
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16	35-32-102. Genetic testing; prohibitions; exceptions.							
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18	(a) Except as provided in subsection (b) of this							
19	section, no person conducting genetic analysis testing							
20	shall do any of the following without the informed consent							
21	of the individual or the individual's authorized							
22	representative:							

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1 (i) Obtain an individual's genetic information
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  data;
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     (ii) Perform <del>a genetic <u>analysis</u> <u>testing</u> on an</del>
5 individual;
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7
           (iii) Retain an individual's genetic information
8
   data;
9
      (iv) Disclose an individual's genetic
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11 information data.
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13 (b) Except as otherwise prohibited by law, an
   individual's genetic information data may be obtained,
14
   retained, disclosed and used without informed consent for:
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        (xi) Services limited to storage, retrieval,
   handling or transmission of genetic information data by a
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    third party service provider pursuant to a contract or
20 other obligation;
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Τ	(c) To safeguard the privacy, confidentiality,							
2	security and integrity of a consumer's genetic data, a							
3	direct to consumer genetic testing company shall:							
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5	(i) Provide clear and complete information							
6	regarding the company's policies and procedures for the							
7	collection, use or disclosure of genetic data by making							
8	available to a consumer:							
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10	(A) A high-level privacy policy overview							
11	that includes essential information about the company's							
12	collection, use or disclosure of genetic data; and							
13								
14	(B) A prominent, publicly available privacy							
15	notice that includes, at a minimum, information about the							
16	company's data collection, consent, use, access,							
17	disclosure, transfer, security and retention and deletion							
18	practices.							
19								
20	(ii) Obtain a consumer's consent for the							
21	collection, use or disclosure of the consumer's genetic							
22	data including, at a minimum:							

1	(A) Initial express consent that describes
2	the uses of the genetic data collected through the genetic
3	testing product or service, and specifies who has access to
4	test results and how the genetic data may be shared;
5	
6	(B) Separate express consent for
7	transferring or disclosing the consumer's genetic data to
8	any person other than the company's vendors and service
9	providers, or for using genetic data beyond the primary
10	purpose of the genetic testing product or service and
11	inherent contextual uses;
12	
13	(C) Separate express consent for the
14	retention of any biological sample provided by the consumer
15	following completion of the initial testing service
16	requested by the consumer;
16 17	
17	requested by the consumer;
17 18	requested by the consumer; (D) Informed consent in compliance with the
17 18 19	requested by the consumer; (D) Informed consent in compliance with the federal policy for the protection of human research

1	company for the purpose of publication or generalizable
2	knowledge; and
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4	(E) Separate express consent for marketing
5	to a consumer based on the consumer's genetic data, or for
6	marketing by a third party person to a consumer based on
7	the consumer having ordered or purchased a genetic testing
8	product or service. Marketing does not include the
9	provision of customized content or offers on the websites
10	or through the applications or services provided by a
11	direct to consumer genetic testing company with a
12	first-party relationship to the customer.
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14	(iii) Require valid legal process for disclosing
15	genetic data to law enforcement or any other government
16	agency without a consumer's express written consent;
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18	(iv) Develop, implement and maintain a
19	comprehensive security program that protects a consumer's
20	genetic data against unauthorized access, use or
21	disclosure; and
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23	(v) Provide a process for a consumer to:
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1 2 (A) Access the consumer's genetic data; 3 4 (B) Delete the consumer's account and genetic data; and 5 6 7 (C) Request and obtain the destruction of 8 the consumer's biological sample. 9 10 (d) Notwithstanding any other provisions in this section, a direct to consumer genetic testing company shall 11 12 not disclose a consumer's genetic data to any entity offering health insurance, life insurance or long-term care 13 insurance, or to any employer of the consumer without the 14 15 consumer's written consent. 16 17 35-32-103. Genetic data; inspection; retention. 18 19 (a) An individual or the individual's authorized 20 representative may inspect, correct and obtain genetic

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information data about the individual.

1	(b)	A	person	conducting	genetic	analysis	<u>-testing</u>
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2 shall destroy an individual's genetic information data upon

3 request by the individual or the individual's authorized

4 representative unless:

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6 (i) The <u>information</u> <u>data</u> was obtained pursuant

7 to W.S. 35-32-102(b); or

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9 (ii) Retention of the <u>information</u> data is

10 necessary for a purpose disclosed to the individual or

11 representative in the informed consent.

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13 (c) Genetic <u>information</u> <u>data</u> about an individual

14 obtained pursuant to W.S. 35-32-102(b) shall be used solely

15 for the purposes obtained and shall be destroyed or

16 returned to the individual or the individual's authorized

17 representative upon completion of the purposes for which

18 the information data was obtained or in accordance with

19 law.

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21 35-32-104. Criminal penalty; private right of action.

1 (b) An individual whose rights have been violated 2 under the provisions of this chapter may bring a civil 3 action to enjoin or restrain any violation of this chapter 4 and may in the same action seek damages from the person 5 violating this chapter. Prior to filing an action under this subsection the individual shall give notice in writing 6 to the alleged violator stating fully the nature of the 7 8 alleged violation. The alleged violator shall have not more than sixty (60) days from the date notice is provided 9 10 to cure any violation. If, after sixty (60) days the violation has not been cured, the individual may bring a 11 12 civil action. A prevailing party in an action brought under 13 this subsection may recover all costs and expenses 14 reasonably associated with the action, including but not 15 limited to reasonable attorney fees.

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(c) The attorney general may bring an action in the name of the state or as parens patriae on behalf of consumers to enforce this chapter. In any action brought by the attorney general to enforce this chapter, a person found to have violated this chapter shall be subject to a civil penalty of two thousand five hundred dollars (\$2,500.00) for each violation, the recovery of actual

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- 1 damages incurred by consumers on whose behalf the action
- 2 was brought and costs and reasonable attorneys' fees
- 3 <u>incurred by the office of the attorney general.</u>

- 5 **Section 3.** This act shall not apply to contracts for
- 6 direct to consumer genetic testing entered into prior to
- 7 July 1, 2022.

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9 Section 4. This act is effective July 1, 2022.

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11 (END)