

- 1 HB21
- 2 YRDF66-1
- 3 By Representative Brown
- 4 RFD: Judiciary
- 5 First Read: 06-Feb-24
- 6 PFD: 01-Dec-23



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### SYNOPSIS:

Existing law provides no privacy protection to consumers who submit biological samples for testing to genetic testing companies.

This bill would require genetic testing companies to obtain express consent from consumers in order to retain, use, and share consumers' genetic information with other entities.

This bill would also create a civil penalty for use and disclosure by testing companies of consumer genetic information without consent and provide for enforcement by the Office of the Attorney General.

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#### 19 TO BE ENTITLED

AN ACT

A BILL

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Relating to consumer privacy; to require genetic testing companies to protect the confidentiality of customers' genetic information; to require customer consent for certain uses by genetic testing companies of genetic information; and to further provide a civil penalty for violations of this act to be enforced by the Attorney General.

28 BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:



- 29 Section 1. This act shall be known as the "Alabama 30 Genetic Data Privacy Act."
- 31 Section 2. For purposes of this act, the following 32 words have the following meanings:
- 33 (1) BIOLOGICAL SAMPLE. Any human material known to 34 contain DNA, including, but not limited to, tissue, saliva, 35 blood, or urine.
- 36 (2) CONSUMER. Any individual who is an Alabama resident.
  - (3) CONTRACTOR. A person that contracts with a genetic testing company to provide a service necessary to the genetic testing company's consumer products or services which requires possession of a consumer's biological sample or genetic data, including laboratory facilities for genetic testing.
- 43 (4) DEIDENTIFIED DATA. Genetic data possessed by a
  44 genetic testing company that cannot reasonably be linked to an
  45 identifiable consumer.
- 46 (5) DNA. Deoxyribonucleic acid.

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- 47 (6) EXPRESS CONSENT. A consumer's acknowledgment or
  48 permission, in writing or captured electronically, to a clear,
  49 meaningful, and prominent written notice regarding the
  50 collection, use, retention, or disclosure of the consumer's
  51 biological sample or genetic data for a specific purpose.
  - (7) GENETIC DATA. a. Any data derived from analysis of a biological sample which concerns a consumer's genetic characteristics and which may include, but is not limited to, any of the following formats or sources:
- 1. Raw data that results from sequencing all or a



- 57 portion of a consumer's extracted DNA.
- 2. Genotypic and phenotypic information obtained from analyzing a consumer's raw sequence data.
- 3. Health information self-reported by the consumer to a genetic testing company to be used by the company in connection with analyzing the consumer's raw sequence data or for product development or scientific research.
- 64 b. Genetic data does not include deidentified data.
- 65 (8) GENETIC TESTING. Laboratory testing of a consumer's 66 biological sample to analyze DNA, including, but not limited 67 to, chromosomes and single nucleotide polymorphisms in order 68 to derive and interpret genetic data.
- (9) GENETIC TESTING COMPANY or COMPANY. Any person that
  directly solicits a biological sample from a consumer for
  analysis in order to provide products or services to the
  consumer which include disclosure of information that may
  include, but is not limited to, the following:
- a. The genetic link of the consumer to certain population groups based on ethnicity, geography, or anthropology.
- 5. The probable relationship of the consumer to other individuals based on matching DNA for purposes that include genealogical research.
- c. Recommendations to the consumer for managing
  wellness which are based on physical or metabolic traits,
  lifestyle tendencies, or disease predispositions that are
  associated with genetic markers present in the consumer's DNA.
- Section 3. (a) (1) A genetic testing company shall



- prominently display to a consumer complete information
- 86 regarding the company's policies and procedures governing the
- 87 collection, use, maintenance, and disclosure of genetic data
- in plain language which includes all of the following:
- a. A privacy policy overview that includes basic
- 90 information about the company's collection, use, or disclosure
- 91 of genetic data.
- 92 b. A privacy policy notice that sets forth the complete
- 93 text of the company's collection, consent, use, access,
- 94 disclosure, transfer, security, retention, and deletion
- 95 policies or practices.
- 96 c. A clear and complete notice that the consumer's
- 97 genetic data may be included in deidentified data shared or
- 98 disclosed by the company to a third party for research in
- 99 compliance with the U.S. Department of Health and Human
- 100 Services policy for the protection of human subjects, 45
- 101 C.F.R. Part 46.
- d. A clear description of how to file a complaint
- 103 alleging a violation of this act.
- 104 (2) A genetic testing company shall obtain the
- 105 consumer's initial express consent for all of the following:
- 106 a. Use of the biological sample and resulting genetic
- data to provide the product or service ordered by the
- 108 consumer.
- b. Identification of who may have access to the
- 110 biological sample, genetic data, and test results, including a
- 111 contractor, in order to fulfill the consumer's order.
- 112 c. Permission to retain the biological sample and



- genetic data for future testing for other products or services offered by the company.
- d. Acknowledgment that the company may seek express

  consent in the future to transfer the biological sample or

  disclose the genetic data to a third party other than a

  contractor for a reason other than fulfillment of an order for
- e. Permission to market additional customized products and services to the consumer through the company's online account portal or electronic application provided to the consumer.

the company's products or services.

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- (3) A genetic testing company shall obtain the
  consumer's express consent every time the company does any of
  the following:
- a. Transferring the biological sample or disclosing the
  genetic data to a third party other than a contractor for a
  reason other than fulfillment of an order for the company's
  products or services.
- b. Using the biological sample or genetic data for a purpose other than the company's products or services ordered by the consumer.
- 134 c. Sharing the consumer's name with a third party to
  135 market the third party's products and services to the
  136 consumer.
- (4) A genetic testing company shall obtain the
  consumer's informed consent to transfer the biological sample
  or disclose the consumer's genetic data in compliance with 45

  C.F.R. Part 46, in the following cases:



- a. For independent research conducted by a third party.
- b. For research conducted under the sponsorship of the
- 143 genetic testing company for the purpose of product or service
- 144 research and development, scientific publication, or promotion
- of the company.
- 146 (5)a. A genetic testing company shall provide a process
- for the consumer to do all of the following:
- 148 1. Access the consumer's genetic data.
- 149 2. Delete the consumer's account.
- 3. Request the destruction of the consumer's biological
- 151 sample and genetic data.
- 4. Revoke any express or informed consent given.
- 153 b. 1. If the consumer requests the destruction of the
- 154 consumer's biological sample and genetic data, the company
- shall comply with the request as soon as reasonably possible,
- but no more than 30 days after the request is made.
- 2. If the consumer revokes any express or informed
- 158 consent given that resulted in the transfer of the consumer's
- 159 biological sample or disclosure of the consumer's genetic data
- 160 to a third party, the company shall secure the return of the
- 161 biological sample and the genetic data as soon as reasonably
- possible, but no more than 60 days after the revocation is
- 163 tendered.
- 164 (b) A genetic testing company may not do any of the
- 165 following without a consumer's express written consent:
- 166 (1) Disclose a consumer's genetic data to any law
- 167 enforcement or other governmental agency, unless the
- 168 disclosure is made pursuant to a valid search warrant,



- 169 subpoena, or court order.
- 170 (2) Disclose a consumer's genetic data to any person 171 issuing health, life, disability, or long-term care insurance.
- 172 (3) Disclose a consumer's genetic data to any employer 173 or prospective employer of the consumer.
- Section 4. (a) A contract between the genetic testing

  company and a contractor shall prohibit the contractor from

  using, retaining, or disclosing any biological sample,

  extracted genetic material, genetic data, or information

  identifying the consumer for any purpose other than performing

  the service specified in the contract.
- (b) A contractor shall be subject to the same

  confidentiality obligation as the company, consistent with

  each express consent given or withheld by a consumer with

  respect to using, retaining, or disclosing the consumer's

  biological sample, extracted genetic material, genetic data,

  or information identifying the consumer.
- Section 5. This act does not apply to any of the following:
- 188 (1) Genetic data that is included in protected health
  189 information that is collected by a covered entity or business
  190 associate as those terms are defined in 45 C.F.R. Parts 160
  191 and 164.
- 192 (2) The collection, use, or retention of biological
  193 samples or genetic data for noncommercial purposes, including
  194 for research and instruction, by a public or private
  195 institution of higher learning or any entity owned or operated
  196 by a public or private institution of higher learning.

# SUP OF ALARMA

- 197 Section 6. (a) Any consumer may report a violation of 198 this act to the the Consumer Division of the Office of the 199 Attorney General.
- 200 (b) The Consumer Division of the Office of the Attorney
  201 General may enforce this act by a civil action in circuit
  202 court to enjoin any practice or conduct in violation of this
  203 act or to recover a civil penalty of up to three thousand
  204 dollars (\$3,000) for each violation.
- 205 (c) Any civil penalty and costs may be waived if the
  206 genetic testing company or contractor has made full
  207 restitution or has paid actual damages to any consumer who has
  208 been injured by a violation of this act.
- 209 (d) In any settlement of a claim or civil action
  210 resulting from a violation of this act, the Office of the
  211 Attorney General shall receive reasonable attorney fees and
  212 costs.
- Section 7. This act shall become effective on October 1, 2024.