

HB21 INTRODUCED



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.

A BILL
TO BE ENTITLED
AN ACT

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.

BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:



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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
37 resident.

38 (3) CONTRACTOR. A person that contracts with a genetic
39 testing company to provide a service necessary to the genetic
40 testing company's consumer products or services which requires
41 possession of a consumer's biological sample or genetic data,
42 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.

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.

52 (7) GENETIC DATA. a. Any data derived from analysis of
53 a biological sample which concerns a consumer's genetic
54 characteristics and which may include, but is not limited to,
55 any of the following formats or sources:

56 1. Raw data that results from sequencing all or a



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57 portion of a consumer's extracted DNA.

58 2. Genotypic and phenotypic information obtained from
59 analyzing a consumer's raw sequence data.

60 3. Health information self-reported by the consumer to
61 a genetic testing company to be used by the company in
62 connection with analyzing the consumer's raw sequence data or
63 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.

69 (9) GENETIC TESTING COMPANY or COMPANY. Any person that
70 directly solicits a biological sample from a consumer for
71 analysis in order to provide products or services to the
72 consumer which include disclosure of information that may
73 include, but is not limited to, the following:

74 a. The genetic link of the consumer to certain
75 population groups based on ethnicity, geography, or
76 anthropology.

77 b. The probable relationship of the consumer to other
78 individuals based on matching DNA for purposes that include
79 genealogical research.

80 c. Recommendations to the consumer for managing
81 wellness which are based on physical or metabolic traits,
82 lifestyle tendencies, or disease predispositions that are
83 associated with genetic markers present in the consumer's DNA.

84 Section 3. (a)(1) A genetic testing company shall



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85 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
88 in plain language which includes all of the following:

89 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.

102 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
107 data to provide the product or service ordered by the
108 consumer.

109 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



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113 genetic data for future testing for other products or services
114 offered by the company.

115 d. Acknowledgment that the company may seek express
116 consent in the future to transfer the biological sample or
117 disclose the genetic data to a third party other than a
118 contractor for a reason other than fulfillment of an order for
119 the company's products or services.

120 e. Permission to market additional customized products
121 and services to the consumer through the company's online
122 account portal or electronic application provided to the
123 consumer.

124 (3) A genetic testing company shall obtain the
125 consumer's express consent every time the company does any of
126 the following:

127 a. Transferring the biological sample or disclosing the
128 genetic data to a third party other than a contractor for a
129 reason other than fulfillment of an order for the company's
130 products or services.

131 b. Using the biological sample or genetic data for a
132 purpose other than the company's products or services ordered
133 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.

137 (4) A genetic testing company shall obtain the
138 consumer's informed consent to transfer the biological sample
139 or disclose the consumer's genetic data in compliance with 45
140 C.F.R. Part 46, in the following cases:



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141 a. For independent research conducted by a third party.

142 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
145 of the company.

146 (5)a. A genetic testing company shall provide a process
147 for the consumer to do all of the following:

148 1. Access the consumer's genetic data.

149 2. Delete the consumer's account.

150 3. Request the destruction of the consumer's biological
151 sample and genetic data.

152 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
155 shall comply with the request as soon as reasonably possible,
156 but no more than 30 days after the request is made.

157 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
162 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,



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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.

174 Section 4. (a) A contract between the genetic testing
175 company and a contractor shall prohibit the contractor from
176 using, retaining, or disclosing any biological sample,
177 extracted genetic material, genetic data, or information
178 identifying the consumer for any purpose other than performing
179 the service specified in the contract.

180 (b) A contractor shall be subject to the same
181 confidentiality obligation as the company, consistent with
182 each express consent given or withheld by a consumer with
183 respect to using, retaining, or disclosing the consumer's
184 biological sample, extracted genetic material, genetic data,
185 or information identifying the consumer.

186 Section 5. This act does not apply to any of the
187 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.



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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.

213 Section 7. This act shall become effective on October
214 1, 2024.