

**HB21 ENROLLED**



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



## HB21 Enrolled

1 Enrolled, An Act,

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

8 BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

9           Section 1. This act shall be known as the "Alabama  
10 Genetic Data Privacy Act."

11           Section 2. For purposes of this act, the following  
12 words have the following meanings:

13           (1) BIOLOGICAL SAMPLE. Any human material known to  
14 contain DNA, including, but not limited to, tissue, saliva,  
15 blood, or urine.

16           (2) CONSUMER. Any individual who is an Alabama  
17 resident.

18           (3) CONTRACTOR. A person that contracts with a genetic  
19 testing company to provide a service necessary to the genetic  
20 testing company's consumer products or services which requires  
21 possession of a consumer's biological sample or genetic data,  
22 including laboratory facilities for genetic testing.

23           (4) DEIDENTIFIED DATA. Genetic data possessed by a  
24 genetic testing company that cannot be used to infer  
25 information about, or otherwise be linked to, an identifiable  
26 consumer and that either meets the requirements for  
27 deidentification of genetic data set forth in 45 C.F.R.  
28 164.514 or is subject to the following:



## HB21 Enrolled

29           a. Administrative and technical measures put in place  
30 by the genetic testing company to ensure that the data cannot  
31 be associated with an identified consumer.

32           b. A public commitment by the genetic testing company  
33 to undertake the following:

34           1. Maintain and use the data only in a deidentified  
35 form.

36           2. Prohibit any attempts to reidentify the data.

37           3. Take legal action to enforce contractual obligations  
38 that prohibit any recipient of the data from attempting to  
39 reidentify the data.

40           (5) DNA. Deoxyribonucleic acid.

41           (6) EXPRESS CONSENT. A consumer's acknowledgment or  
42 permission, in writing or captured electronically, to a clear,  
43 meaningful, and prominent written notice regarding the  
44 collection, use, retention, or disclosure of the consumer's  
45 biological sample or genetic data for a specific purpose.

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

50           1. Raw data that results from sequencing all or a  
51 portion of a consumer's extracted DNA.

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

54           3. Health information self-reported by the consumer to  
55 a genetic testing company to be used by the company in  
56 connection with analyzing the consumer's raw sequence data or



## HB21 Enrolled

57 for product development or scientific research.

58 b. Genetic data does not include deidentified data.

59 (8) GENETIC TESTING. Laboratory testing of a consumer's  
60 biological sample to analyze DNA, including, but not limited  
61 to, chromosomes and single nucleotide polymorphisms in order  
62 to derive and interpret genetic data.

63 (9) GENETIC TESTING COMPANY or COMPANY. Any person,  
64 other than a health care provider, that directly solicits a  
65 biological sample from a consumer for analysis in order to  
66 provide products or services to the consumer which include  
67 disclosure of information that may include, but is not limited  
68 to, the following:

69 a. The genetic link of the consumer to certain  
70 population groups based on ethnicity, geography, or  
71 anthropology.

72 b. The probable relationship of the consumer to other  
73 individuals based on matching DNA for purposes that include  
74 genealogical research.

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

79 (10) HEALTH CARE PROVIDER. Any hospital, as defined in  
80 Section 22-21-20, Code of Alabama 1975, licensed by the State  
81 Board of Health, and any physician, nurse, or other licensed  
82 medical practitioner, whether in individual, group,  
83 professional corporation, or professional association  
84 practice, which provides diagnostic services or treatment for



## HB21 Enrolled

85 a patient of such hospital, physician, nurse, or other  
86 licensed medical practitioner.

87 Section 3. (a)(1) A genetic testing company shall  
88 prominently display to a consumer complete information  
89 regarding the company's policies and procedures governing the  
90 collection, use, maintenance, and disclosure of genetic data  
91 in plain language which includes all of the following:

92 a. A privacy policy overview that includes basic  
93 information about the company's collection, use, or disclosure  
94 of genetic data.

95 b. A privacy policy notice that sets forth the complete  
96 text of the company's collection, consent, use, access,  
97 disclosure, transfer, security, retention, and deletion  
98 policies or practices.

99 c. A clear and complete notice that the consumer's  
100 genetic data may be included in deidentified data shared or  
101 disclosed by the company to a third party for research in  
102 compliance with the U.S. Department of Health and Human  
103 Services policy for the protection of human subjects, 45  
104 C.F.R. Part 46.

105 d. A clear description of how to file a complaint  
106 alleging a violation of this act.

107 (2) A genetic testing company shall obtain the  
108 consumer's initial express consent for all of the following:

109 a. Use of the biological sample and resulting genetic  
110 data to provide the product or service ordered by the  
111 consumer.

112 b. Identification of who may have access to the



## HB21 Enrolled

113 biological sample, genetic data, and test results, including a  
114 contractor, in order to fulfill the consumer's order.

115 c. Permission to retain the biological sample and  
116 genetic data for future testing for other products or services  
117 offered by the company.

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

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

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

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

133 c. Marketing to a consumer based on the consumer's  
134 genetic data, or marketing to a consumer by a third party  
135 based on the consumer having ordered or purchased a genetic  
136 testing product or service. Marketing does not include the  
137 provision of customized content or offers on websites or  
138 through the applications or services provided by the  
139 direct-to-consumer genetic testing company with the  
140 first-party relationship to the consumer.



## HB21 Enrolled

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

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

146 b. For research conducted under the sponsorship of the  
147 genetic testing company for the purpose of product or service  
148 research and development, scientific publication, or promotion  
149 of the company.

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

152 1. Access the consumer's genetic data.

153 2. Delete the consumer's account.

154 3. Request the destruction of the consumer's biological  
155 sample and genetic data.

156 4. Revoke any express or informed consent given.

157 b. 1. If the consumer requests the destruction of the  
158 consumer's biological sample and genetic data, the company  
159 shall comply with the request as soon as reasonably possible,  
160 but no more than 30 days after the request is made.

161 2. If the consumer revokes any express or informed  
162 consent given that resulted in the transfer of the consumer's  
163 biological sample or disclosure of the consumer's genetic data  
164 to a third party, the company shall secure the return of the  
165 biological sample and the genetic data as soon as reasonably  
166 possible, but no more than 60 days after the revocation is  
167 tendered.

168 (b) A genetic testing company may disclose a consumer's



## HB21 Enrolled

169 genetic data to any law enforcement agency pursuant to a valid  
170 legal process. When a law enforcement agency requests data  
171 from a genetic testing company, the company shall not disclose  
172 the existence of the valid legal process or the fact of the  
173 company's compliance specifically to the party to whom the  
174 valid legal process pertains. Nothing in this subsection shall  
175 prevent a company from publishing a transparency report that  
176 details the number and types of law enforcement requests  
177 received and the number of times categories of information are  
178 shared, nor prevent a company from complying with other laws  
179 or policies, including a company's privacy policy.

180 (c) A genetic testing company may not do any of the  
181 following without a consumer's express written consent:

182  
183 (1) Disclose a consumer's genetic data to any person  
184 issuing health, life, disability, or long-term care insurance.

185 (2) Disclose a consumer's genetic data to any employer  
186 or prospective employer of the consumer.

187 Section 4. (a) A contract between the genetic testing  
188 company and a contractor shall prohibit the contractor from  
189 using, retaining, or disclosing any biological sample,  
190 extracted genetic material, genetic data, or information  
191 identifying the consumer for any purpose other than performing  
192 the service specified in the contract.

193 (b) A contractor shall be subject to the same  
194 confidentiality obligation as the company, consistent with  
195 each express consent given or withheld by a consumer with  
196 respect to using, retaining, or disclosing the consumer's





## HB21 Enrolled

197 biological sample, extracted genetic material, genetic data,  
198 or information identifying the consumer.

199 Section 5. This act does not apply to any of the  
200 following:

201 (1) A covered entity or business associate as those  
202 terms are defined in 45 C.F.R. Parts 160 and 164.

203 (2) The collection, use, or retention of biological  
204 samples or genetic data for noncommercial purposes, including  
205 for research and instruction, by a public or private  
206 institution of higher learning or any entity owned or operated  
207 by a public or private institution of higher learning.

208 (3) Biological samples or genetic data lawfully  
209 obtained by law enforcement pursuant to a criminal  
210 investigation.

211 Section 6. (a) Any consumer may report a violation of  
212 this act to the the Consumer Division of the Office of the  
213 Attorney General.

214 (b) The Consumer Division of the Office of the Attorney  
215 General may enforce this act by a civil action in circuit  
216 court to enjoin any practice or conduct in violation of this  
217 act or to recover a civil penalty of up to three thousand  
218 dollars (\$3,000) for each violation.

219 (c) Any civil penalty and costs may be waived if the  
220 genetic testing company or contractor has made full  
221 restitution or has paid actual damages to any consumer who has  
222 been injured by a violation of this act.

223 (d) In any settlement of a claim or civil action  
224 resulting from a violation of this act, the Office of the



## HB21 Enrolled

225 Attorney General shall receive reasonable attorney fees and  
226 costs.

227 Section 7. This act shall become effective on October  
228 1, 2024.



**HB21 Enrolled**

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Speaker of the House of Representatives

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President and Presiding Officer of the Senate

House of Representatives

I hereby certify that the within Act originated in and was passed by the House 20-Feb-24, as amended.

John Treadwell  
Clerk

Senate	<b>08-May-24</b>	Amended and Passed
House	<b>08-May-24</b>	Concurred in Senate Amendment