



**House Judiciary Reported Substitute for HB21**

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28

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:

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

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

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

(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,



## House Judiciary Reported Substitute for HB21

29 including laboratory facilities for genetic testing.

30 (4) DEIDENTIFIED DATA. Genetic data possessed by a  
31 genetic testing company that cannot reasonably be linked to an  
32 identifiable consumer.

33 (5) DNA. Deoxyribonucleic acid.

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

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

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

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

47 3. Health information self-reported by the consumer to  
48 a genetic testing company to be used by the company in  
49 connection with analyzing the consumer's raw sequence data or  
50 for product development or scientific research.

51 b. Genetic data does not include deidentified data.

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

56 (9) GENETIC TESTING COMPANY or COMPANY. Any person,



## House Judiciary Reported Substitute for HB21

57 other than a health care provider, that directly solicits a  
58 biological sample from a consumer for analysis in order to  
59 provide products or services to the consumer which include  
60 disclosure of information that may include, but is not limited  
61 to, the following:

62 a. The genetic link of the consumer to certain  
63 population groups based on ethnicity, geography, or  
64 anthropology.

65 b. The probable relationship of the consumer to other  
66 individuals based on matching DNA for purposes that include  
67 genealogical research.

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

72 (10) HEALTH CARE PROVIDER. Any hospital, as defined in  
73 Section 22-21-20, Code of Alabama 1975, licensed by the State  
74 Board of Health, and any physician, nurse, or other licensed  
75 medical practitioner, whether in individual, group,  
76 professional corporation, or professional association  
77 practice, which provides diagnostic services or treatment for  
78 a patient of such hospital, physician, nurse, or other  
79 licensed medical practitioner.

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



## House Judiciary Reported Substitute for HB21

85 a. A privacy policy overview that includes basic  
86 information about the company's collection, use, or disclosure  
87 of genetic data.

88 b. A privacy policy notice that sets forth the complete  
89 text of the company's collection, consent, use, access,  
90 disclosure, transfer, security, retention, and deletion  
91 policies or practices.

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

98 d. A clear description of how to file a complaint  
99 alleging a violation of this act.

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

102 a. Use of the biological sample and resulting genetic  
103 data to provide the product or service ordered by the  
104 consumer.

105 b. Identification of who may have access to the  
106 biological sample, genetic data, and test results, including a  
107 contractor, in order to fulfill the consumer's order.

108 c. Permission to retain the biological sample and  
109 genetic data for future testing for other products or services  
110 offered by the company.

111 d. Acknowledgment that the company may seek express  
112 consent in the future to transfer the biological sample or



## House Judiciary Reported Substitute for HB21

113 disclose the genetic data to a third party other than a  
114 contractor for a reason other than fulfillment of an order for  
115 the company's products or services.

116 e. Permission to market additional customized products  
117 and services to the consumer through the company's online  
118 account portal or electronic application provided to the  
119 consumer.

120 (3) A genetic testing company shall obtain the  
121 consumer's express consent every time the company does any of  
122 the following:

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

127 b. Using the biological sample or genetic data for a  
128 purpose other than the company's products or services ordered  
129 by the consumer.

130 c. Sharing the consumer's name with a third party to  
131 market the third party's products and services to the  
132 consumer.

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

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

138 b. For research conducted under the sponsorship of the  
139 genetic testing company for the purpose of product or service  
140 research and development, scientific publication, or promotion



## House Judiciary Reported Substitute for HB21

141 of the company.

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

144 1. Access the consumer's genetic data.

145 2. Delete the consumer's account.

146 3. Request the destruction of the consumer's biological  
147 sample and genetic data.

148 4. Revoke any express or informed consent given.

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

153 2. If the consumer revokes any express or informed  
154 consent given that resulted in the transfer of the consumer's  
155 biological sample or disclosure of the consumer's genetic data  
156 to a third party, the company shall secure the return of the  
157 biological sample and the genetic data as soon as reasonably  
158 possible, but no more than 60 days after the revocation is  
159 tendered.

160 (b) A genetic testing company may disclose a consumer's  
161 genetic data to any law enforcement agency pursuant to a valid  
162 subpoena. When a law enforcement agency requests data from a  
163 genetic testing company, the company shall not disclose the  
164 existence of the subpoena or the fact of the company's  
165 compliance.

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

168



## House Judiciary Reported Substitute for HB21

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

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

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

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

185 Section 5. This act does not apply to any of the  
186 following:

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

189 (2) The collection, use, or retention of biological  
190 samples or genetic data for noncommercial purposes, including  
191 for research and instruction, by a public or private  
192 institution of higher learning or any entity owned or operated  
193 by a public or private institution of higher learning.

194 Section 6. (a) Any consumer may report a violation of  
195 this act to the the Consumer Division of the Office of the  
196 Attorney General.



**House Judiciary Reported Substitute for HB21**

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

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

206 (d) In any settlement of a claim or civil action  
207 resulting from a violation of this act, the Office of the  
208 Attorney General shall receive reasonable attorney fees and  
209 costs.

210 Section 7. This act shall become effective on October  
211 1, 2024.