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GENETIC INFORMATION PRIVACY ACT

2021 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Curtis S. Bramble

House Sponsor: _____

LONG TITLE

General Description:

This bill enacts the Genetic Information Privacy Act.

Highlighted Provisions:

This bill:

- ▶ defines terms;
- ▶ requires a direct-to-consumer genetic testing company to:
 - provide a consumer clear information regarding the company's collection, use, and disclosure of genetic data;
 - provide a consumer a publicly available privacy notice;
 - obtain a consumer's consent for certain collection, use, or disclosure of the consumer's genetic data;
 - protect a consumer's genetic data;
 - allow a consumer to access and delete the consumer's genetic data; and
 - upon request, destroy a consumer's biological sample;
- ▶ prohibits a direct-to-consumer genetic testing company from disclosing a consumer's genetic data to certain persons; and
- ▶ empowers the Office of the Attorney General to take enforcement action against violators.

Money Appropriated in this Bill:

None



28 **Other Special Clauses:**

29 None

30 **Utah Code Sections Affected:**

31 ENACTS:

32 **13-58-101**, Utah Code Annotated 1953

33 **13-58-102**, Utah Code Annotated 1953

34 **13-58-103**, Utah Code Annotated 1953

35 **13-58-201**, Utah Code Annotated 1953

36 **13-58-202**, Utah Code Annotated 1953

37 **13-58-301**, Utah Code Annotated 1953



39 *Be it enacted by the Legislature of the state of Utah:*

40 Section 1. Section **13-58-101** is enacted to read:

41 **CHAPTER 58. GENETIC INFORMATION PRIVACY ACT**

42 **Part 1. General Provisions**

43 **13-58-101. Title.**

44 This chapter is known as the "Genetic Information Privacy Act."

45 Section 2. Section **13-58-102** is enacted to read:

46 **13-58-102. Definitions.**

47 As used in this chapter:

48 (1) "Biological sample" means any human material known to contain DNA, including
49 tissue, blood, urine, or saliva.

50 (2) "Consumer" means an individual who is a resident of the state.

51 (3) "Deidentified data" means data that:

52 (a) cannot reasonably be linked to an identifiable individual; and

53 (b) possessed by a company that:

54 (i) takes administrative and technical measures to ensure that the data cannot be
55 associated with a particular consumer;

56 (ii) makes a public commitment to maintain and use data in deidentified form and not
57 attempt to reidentify data; and

58 (iii) enters into legally enforceable contractual obligation that prohibits a recipient of

59 the data from attempting to reidentify the data.

60 (4) "Direct-to-consumer genetic testing company" or "company" means an entity that:

61 (a) offers consumer genetic testing products or services directly to consumers; or

62 (b) collects, uses, or analyzes genetic data that a consumer provides to the entity.

63 (5) "DNA" means deoxyribonucleic acid.

64 (6) "Express consent" means a consumer's affirmative response to a clear, meaningful,
65 and prominent notice regarding the collection, use, or disclosure of genetic data for a specific
66 purpose.

67 (7) (a) "Genetic data" means any data, regardless of format, concerning a consumer's
68 genetic characteristics.

69 (b) "Genetic data" includes:

70 (i) raw sequence data that result from sequencing all or a portion of a consumer's
71 extracted DNA;

72 (ii) genotypic and phenotypic information obtained from analyzing a consumer's raw
73 sequence data; and

74 (iii) self-reported health information regarding a consumer's health conditions that the
75 consumer provides to a company that the company:

76 (A) uses for scientific research or product development; and

77 (B) analyzes in connection with the consumer's raw sequence data.

78 (c) "Genetic data" does not include deidentified data.

79 (8) "Genetic testing" means a laboratory test of a consumer's complete DNA, regions of
80 DNA, chromosomes, genes, or gene products to determine the presence of genetic
81 characteristics of the consumer.

82 Section 3. Section **13-58-103** is enacted to read:

83 **13-58-103. Limitations.**

84 This chapter does not apply to protected health information that is collected by a
85 covered entity or business associate as those terms are defined in 45 C.F.R Parts 160 and 164.

86 Section 4. Section **13-58-201** is enacted to read:

87 **Part 2. Consumer Genetic Data**

88 **13-58-201. Consumer genetic information -- Privacy notice -- Consent -- Access --**
89 **Deletion -- Destruction.**

90 (1) A direct-to-consumer genetic testing company shall:

91 (a) provide to a consumer:

92 (i) essential information about the company's collection, use, and disclosure of genetic
93 data; and

94 (ii) a prominent, publicly available privacy notice that includes information about the
95 company's data collection, consent, use, access, disclosure, transfer, security, retention, and
96 deletion practices;

97 (b) obtain a consumer's initial express consent for collection, use, or disclosure of the
98 consumer's genetic data that:

99 (i) clearly describes the company's use of the genetic data that the company collects
100 through the company's genetic testing product or service;

101 (ii) specifies who has access to test results; and

102 (iii) specifies how the company may share the genetic data;

103 (c) if the company engages in any of the following, obtain a consumer's:

104 (i) separate express consent for:

105 (A) each transfer or disclosure of the consumer's genetic data to any person other than
106 the company's vendors and service providers;

107 (B) each use of genetic data beyond the primary purpose of the company's genetic
108 testing product or service; or

109 (C) the company's retention of any biological sample provided by the consumer
110 following the company's completion of the initial testing service requested by the consumer;

111 (ii) informed consent in accordance with the Federal Policy for the Protection of
112 Human Subjects, 45 C.F.R. Part 46, for transfer or disclosure of the consumer's genetic data to
113 a third party for:

114 (A) research purposes; or

115 (B) research conducted under the control of the company for the purpose of publication
116 or generalizable knowledge; and

117 (iii) express consent for:

118 (A) marketing to a consumer based on the consumer's genetic data; or

119 (B) marketing by a third party person to a consumer based on the consumer having
120 ordered or purchased a genetic testing product or service;

121 (d) require valid legal process for the company's disclosure of a consumer's genetic
122 data to law enforcement or any government entity without the consumer's express written
123 consent;

124 (e) develop, implement, and maintain a comprehensive security program to protect a
125 consumer's genetic data against unauthorized access, use, or disclosure; and

126 (f) provide a process for a consumer to:

127 (i) access the consumer's genetic data;

128 (ii) delete the consumer's account and genetic data; and

129 (iii) require the company to destroy the consumer's biological sample.

130 (2) Notwithstanding Subsection (1)(c)(iii), a direct-to-consumer genetic testing
131 company with a first-party relationship to a consumer may, without obtaining the consumer's
132 express consent, provide customized content or offers on the company's website or through the
133 company's application or service.

134 Section 5. Section **13-58-202** is enacted to read:

135 **13-58-202. Prohibited disclosures.**

136 A direct-to-consumer genetic testing company may not disclose a consumer's genetic
137 data to:

138 (1) an entity that offers health insurance, life insurance, or long-term care insurance; or

139 (2) an employer of the consumer.

140 Section 6. Section **13-58-301** is enacted to read:

141 **Part 3. Enforcement**

142 **13-58-301. Enforcement powers of the attorney general.**

143 (1) The attorney general may enforce this chapter.

144 (2) The attorney general may initiate a civil enforcement action against a person for
145 violating this chapter.

146 (3) In an action to enforce this chapter, the attorney general may recover:

147 (a) actual damages to the consumer;

148 (b) costs;

149 (c) attorney fees; and

150 (d) \$2,500 for each violation of this chapter.