

**Senator Curtis S. Bramble** proposes the following substitute bill:

**GENETIC INFORMATION PRIVACY ACT**

2021 GENERAL SESSION

STATE OF UTAH

**Chief Sponsor: Curtis S. Bramble**

House Sponsor: \_\_\_\_\_

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**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.

**1st Sub. S.B. 227**



26 **Money Appropriated in this Bill:**

27 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:

80 (a) a laboratory test of a consumer's complete DNA, regions of DNA, chromosomes,  
81 genes, or gene products to determine the presence of genetic characteristics of the consumer; or

82 (b) an interpretation of a consumer's genetic data.

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

84 **13-58-103. Limitations.**

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

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

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**Part 2. Consumer Genetic Data**

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

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

(a) provide to a consumer:

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

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

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

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

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

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

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

(i) separate express consent for:

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

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

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

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

(A) research purposes; or

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

(iii) express consent for:

- 119 (A) marketing to a consumer based on the consumer's genetic data; or  
120 (B) marketing by a third party person to a consumer based on the consumer having  
121 ordered or purchased a genetic testing product or service;  
122 (d) require valid legal process for the company's disclosure of a consumer's genetic  
123 data to law enforcement or any government entity without the consumer's express written  
124 consent;  
125 (e) develop, implement, and maintain a comprehensive security program to protect a  
126 consumer's genetic data against unauthorized access, use, or disclosure; and  
127 (f) provide a process for a consumer to:  
128 (i) access the consumer's genetic data;  
129 (ii) delete the consumer's account and genetic data; and  
130 (iii) destroy the consumer's biological sample.  
131 (2) Notwithstanding Subsection (1)(c)(iii), a direct-to-consumer genetic testing  
132 company with a first-party relationship to a consumer may, without obtaining the consumer's  
133 express consent, provide customized content or offers on the company's website or through the  
134 company's application or service.

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

136 **13-58-202. Prohibited disclosures.**

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

- 139 (1) an entity that offers health insurance, life insurance, or long-term care insurance; or  
140 (2) an employer of the consumer.

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

142 **Part 3. Enforcement**

143 **13-58-301. Enforcement powers of the attorney general.**

- 144 (1) The attorney general may enforce this chapter.  
145 (2) The attorney general may initiate a civil enforcement action against a person for  
146 violating this chapter.  
147 (3) In an action to enforce this chapter, the attorney general may recover:  
148 (a) actual damages to the consumer;  
149 (b) costs;

- 150            (c) attorney fees; and
- 151            (d) \$2,500 for each violation of this chapter.