

**GENETIC PRIVACY AMENDMENTS**

2022 GENERAL SESSION

STATE OF UTAH

**Chief Sponsor: Michael S. Kennedy**

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

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**LONG TITLE**

**General Description:**

This bill amends the Genetic Testing Privacy Act regarding genetic procedures.

**Highlighted Provisions:**

This bill:

- ▶ amends the definition of "DNA" and "private genetic information";
- ▶ defines "genetic procedure";
- ▶ amends restrictions on employers regarding requests or inquiries about genetic procedures;
- ▶ amends restrictions on health insurers regarding requests or inquiries about genetic procedures; and
- ▶ makes technical and conforming changes.

**Money Appropriated in this Bill:**

None

**Other Special Clauses:**

None

**Utah Code Sections Affected:**

AMENDS:

**26-45-102**, as enacted by Laws of Utah 2002, Chapter 120

**26-45-103**, as enacted by Laws of Utah 2002, Chapter 120

**26-45-104**, as enacted by Laws of Utah 2002, Chapter 120



28 [26-45-105](#), as enacted by Laws of Utah 2002, Chapter 120

29 REPEALS:

30 [26-45-101](#), as enacted by Laws of Utah 2002, Chapter 120



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

33 Section 1. Section [26-45-102](#) is amended to read:

34 **CHAPTER 45. GENETIC TESTING AND PROCEDURE PRIVACY ACT**

35 **26-45-102. Definitions.**

36 As used in this chapter:

37 (1) "Blood relative" means ~~[a person's]~~ an individual's biologically related:

- 38 (a) parent;
- 39 (b) grandparent;
- 40 (c) child;
- 41 (d) grandchild;
- 42 (e) sibling;
- 43 (f) uncle;
- 44 (g) aunt;
- 45 (h) nephew;
- 46 (i) niece; or
- 47 (j) first cousin.

48 (2) "DNA" means:

49 (a) deoxyribonucleic acid, ribonucleic acid, and chromosomes, which may be analyzed  
50 to detect heritable diseases or conditions, including the identification of carriers, predicting risk  
51 of disease, or establishing a clinical diagnosis[-]; or

52 (b) proteins, enzymes, or other molecules associated with a genetic process, which may  
53 be modified, replaced in part or whole, superseded, or bypassed in function by a health or  
54 medical procedure.

55 (3) "DNA sample" means any human biological specimen from which DNA can be  
56 extracted, or DNA extracted from such specimen.

57 (4) "Employer" means the same as that term is defined in Section [34A-2-103](#).

58 ~~[(4)]~~ (5) (a) "Genetic analysis" or "genetic test" means the testing, detection, or analysis

59 of an identifiable individual's DNA that results in information that is derived from the  
 60 presence, absence, alteration, or mutation of an inherited gene or genes, or the presence or  
 61 absence of a specific DNA marker or markers.

62 (b) "Genetic analysis" or "genetic test" does not mean:

63 (i) a routine physical examination;

64 (ii) a routine chemical, blood, or urine analysis;

65 (iii) a test to identify the presence of drugs or HIV infection; or

66 (iv) a test performed due to the presence of signs, symptoms, or other manifestations of  
 67 a disease, illness, impairment, or other disorder.

68 [~~(5) "Individual" means the person from whose body the DNA sample originated.~~]

69 [~~(6) "Person" means any person, organization, or entity other than the individual.~~]

70 (6) "Genetic procedure" means any therapy, treatment, or medical procedure that is  
 71 intended to:

72 (a) add, remove, alter, activate, change, or cause mutation in an individual's inherited  
 73 DNA; or

74 (b) replace, supersede, or bypass a normal DNA function.

75 (7) "Health care insurance" means the same as that term is defined in Section  
 76 [31A-1-301](#).

77 [~~(7)~~] (8) (a) "Private genetic information" means any information about an identifiable  
 78 individual that:

79 (i) is derived from:

80 (A) the presence, absence, alteration, or mutation of an inherited gene or genes[;]; or

81 (B) the presence or absence of a specific DNA marker or markers[;]; and [which]

82 (ii) has been obtained:

83 [~~(i)~~] (A) from a genetic test or analysis of the individual's DNA; [or]

84 [~~(ii)~~] (B) from a genetic test or analysis of [a person's DNA to whom the individual is]  
 85 the DNA of a blood relative[;] of the individual; or

86 (C) from a genetic procedure.

87 (b) "Private genetic information" does not include information that is derived from:

88 (i) a routine physical examination;

89 (ii) a routine chemical, blood, or urine analysis;

- 90 (iii) a test to identify the presence of drugs or HIV infection; or
- 91 (iv) a test performed due to the presence of signs, symptoms, or other manifestations of
- 92 a disease, illness, impairment, or other disorder.

93 Section 2. Section **26-45-103** is amended to read:

94 **26-45-103. Restrictions on employers.**

95 (1) Except as provided in Subsection (2), an employer~~[, as defined in Section~~  
96 ~~34A-2-103,]~~ may not in connection with a hiring, promotion, retention, or other related  
97 decision:

98 (a) access or otherwise take into consideration private genetic information about an  
99 individual;

100 (b) request or require an individual to consent to a release for the purpose of accessing  
101 private genetic information about the individual;

102 (c) request or require an individual or ~~[his]~~ the individual's blood relative to submit to:

103 (i) a genetic test; ~~[and]~~ or

104 (ii) a genetic procedure; or

105 (d) inquire into or otherwise take into consideration the fact that an individual or ~~[his]~~  
106 the individual's blood relative has:

107 (i) taken or refused to take a genetic test~~[-];~~ or

108 (ii) undergone or refused to undergo a genetic procedure.

109 (2) (a) Notwithstanding Subsection (1), an employer may seek an order compelling the  
110 disclosure of private genetic information held by an individual or third party pursuant to  
111 Subsection (2)(b) in connection with:

112 (i) an employment-related judicial or administrative proceeding in which the individual  
113 has placed his health at issue; or

114 (ii) an employment-related decision in which the employer has a reasonable basis to  
115 believe that the individual's health condition poses a real and unjustifiable safety risk requiring  
116 the change or denial of an assignment.

117 (b) (i) An order compelling the disclosure of private genetic information pursuant to  
118 this Subsection (2) may only be entered upon a finding that:

119 (A) other ways of obtaining the private information are not available or would not be  
120 effective; and

121 (B) there is a compelling need for the private genetic information which substantially  
122 outweighs the potential harm to the privacy interests of the individual.

123 (ii) An order compelling the disclosure of private genetic information pursuant to this  
124 Subsection (2) shall:

125 (A) limit disclosure to those parts of the record containing information essential to  
126 fulfill the objective of the order;

127 (B) limit disclosure to those persons whose need for the information is the basis of the  
128 order; and

129 (C) include such other measures as may be necessary to limit disclosure for the  
130 protection of the individual.

131 Section 3. Section **26-45-104** is amended to read:

132 **26-45-104. Restrictions on health insurers.**

133 (1) Except as provided in Subsection (2), an insurer offering health care insurance [~~as~~  
134 ~~defined in Section 31A-1-301~~] may not in connection with the offer or renewal of an insurance  
135 product or in the determination of premiums, coverage, renewal, cancellation, or any other  
136 underwriting decision that pertains directly to the individual or any group of which the  
137 individual is a member that purchases insurance jointly:

138 (a) access or otherwise take into consideration private genetic information about an  
139 asymptomatic individual;

140 (b) request or require an asymptomatic individual to consent to a release for the  
141 purpose of accessing private genetic information about the individual;

142 (c) request or require an asymptomatic individual or [~~his~~] the individual's blood  
143 relative to submit to a genetic test; [~~and~~]

144 (d) inquire into or otherwise take into consideration the fact that an asymptomatic  
145 individual or [~~his~~] the individual's blood relative has taken or refused to take a genetic test[-];

146 (e) request or require an individual or the individual's blood relative to submit to a  
147 genetic procedure; or

148 (f) inquire into or otherwise take into consideration the fact that an individual or the  
149 individual's blood relative has undergone or refused to undergo a genetic procedure.

150 (2) An insurer offering health care insurance:

151 (a) may request information regarding the necessity of a genetic test or a genetic

152 procedure, but not the results of the test or procedure, if a claim for payment for the test or  
153 procedure has been made against an individual's health insurance policy;

154 (b) may request that portion of private genetic information that is necessary to  
155 determine the insurer's obligation to pay for health care services where:

156 (i) the primary basis for rendering such services to an individual is the result of a  
157 genetic test; and

158 (ii) a claim for payment for such services has been made against the individual's health  
159 insurance policy;

160 (c) may only store information obtained under this Subsection (2) in accordance with  
161 the provisions of the Health Insurance Portability and Accountability Act of 1996; and

162 (d) may only use or otherwise disclose the information obtained under this Subsection  
163 (2) in connection with a proceeding to determine the obligation of an insurer to pay for a  
164 genetic test or health care services, provided that, in accordance with the provisions of the  
165 Health Insurance Portability and Accountability Act of 1996, the insurer makes a reasonable  
166 effort to limit disclosure to the minimum necessary to carry out the purposes of the disclosure.

167 (3) (a) An insurer may, to the extent permitted by Subsection (2), seek an order  
168 compelling the disclosure of private genetic information held by an individual or third party.

169 (b) An order authorizing the disclosure of private genetic information pursuant to this  
170 Subsection (2) shall:

171 (i) limit disclosure to those parts of the record containing information essential to  
172 fulfill the objectives of the order;

173 (ii) limit disclosure to those persons whose need for the information is the basis for the  
174 order; and

175 (iii) include such other measures as may be necessary to limit disclosure for the  
176 protection of the individual.

177 (4) Nothing in this section may be construed as restricting the ability of an insurer to  
178 use information other than private genetic information to take into account the health status of  
179 an individual, group, or population in determining premiums or making other underwriting  
180 decisions.

181 (5) Nothing in this section may be construed as:

182 (a) requiring an insurer to pay for genetic testing or a genetic procedure; or

183 (b) prohibiting the use of step-therapy protocols.

184 (6) Information maintained by an insurer about an individual under this section may be  
185 redisclosed:

186 (a) to protect the interests of the insurer in detecting, prosecuting, or taking legal action  
187 against criminal activity, fraud, material misrepresentations, and material omissions;

188 (b) to enable business decisions to be made about the purchase, transfer, merger,  
189 reinsurance, or sale of all or part of the insurer's business; and

190 (c) to the commissioner of insurance upon formal request.

191 Section 4. Section **26-45-105** is amended to read:

192 **26-45-105. Private right of action.**

193 (1) (a) An individual whose legal rights arising under this chapter have been violated  
194 after June 30, 2003, may recover damages and be granted equitable relief in a civil action.

195 (b) Subsection (1)(a) does not create a legal right prior to the Legislature enacting the  
196 right under this chapter.

197 (2) Any insurance company or employer who violates the legal rights of an individual  
198 arising from this chapter shall be liable to the individual for each separate violation in an  
199 amount equal to:

200 (a) actual damages sustained as a result of the violation;

201 (b) (i) \$100,000 if the violation is the result of an intentional and [~~willful~~] willful act; or

202 (ii) punitive damages if the violation is the result of a malicious act; and

203 (c) reasonable attorneys' fees.

204 Section 5. **Repealer.**

205 This bill repeals:

206 Section **26-45-101**, Title.