

1 **GENETIC PRIVACY AND DISCRIMINATION**

2 2002 GENERAL SESSION

3 STATE OF UTAH

4 **Sponsor: Paul Ray**

5 **This act modifies provisions related to health. The act defines terms. The act prohibits**
6 **employers from using private genetic information for hiring and promotion purposes. The**
7 **act places restrictions on health insurers' use of genetic information with limited exceptions.**
8 **The act provides a private right of action for violations after June 2003. The act authorizes**
9 **the attorney general to enforce the act. The act provides an effective date.**

10 This act affects sections of Utah Code Annotated 1953 as follows:

11 ENACTS:

12 **26-45-101**, Utah Code Annotated 1953

13 **26-45-102**, Utah Code Annotated 1953

14 **26-45-103**, Utah Code Annotated 1953

15 **26-45-104**, Utah Code Annotated 1953

16 **26-45-105**, Utah Code Annotated 1953

17 **26-45-106**, Utah Code Annotated 1953

18 **31A-22-1601**, Utah Code Annotated 1953

19 **31A-22-1602**, Utah Code Annotated 1953

20 **34A-11-101**, Utah Code Annotated 1953

21 **34A-11-102**, Utah Code Annotated 1953

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

23 Section 1. Section **26-45-101** is enacted to read:

24 **CHAPTER 45. GENETIC TESTING PRIVACY ACT**

25 **26-45-101. Title.**

26 This chapter is known as the "Genetic Testing Privacy Act."

27 Section 2. Section **26-45-102** is enacted to read:



28 26-45-102. Definitions.

29 As used in this chapter:

30 (1) "Blood Relative" means a person's biologically related:

31 (a) parent;

32 (b) grandparent;

33 (c) child;

34 (d) grandchild;

35 (e) sibling;

36 (f) uncle;

37 (g) aunt;

38 (h) nephew;

39 (i) niece; or

40 (j) first cousin.

41 (2) "DNA" means deoxyribonucleic acid, ribonucleic acid, and chromosomes, which may
42 be analyzed to detect heritable diseases or conditions, including the identification of carriers,
43 predicting risk of disease, or establishing a clinical diagnosis.

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

46 (4) (a) "Genetic analysis" or "genetic test" means the testing or analysis of an identifiable
47 individual's DNA that results in information that is derived from the presence, absence, alteration,
48 or mutation of an inherited gene or genes, or the presence or absence of a specific DNA marker
49 or markers.

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

51 (i) a routine physical examination;

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

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

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

56 (5) "Individual" means the person from whose body the DNA sample originated.

57 (6) "Person" means any person, organization, or entity other than the individual.

58 (7) (a) "Private genetic information" means any information about an identifiable

59 individual that is derived from the presence, absence, alteration, or mutation of an inherited gene
60 or genes, or the presence or absence of a specific DNA marker or markers, and which has been
61 obtained:

62 (i) from a genetic test or analysis of the individual's DNA; or

63 (ii) from a genetic test or analysis of a person's DNA to whom the individual is a blood
64 relative.

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

66 (i) a routine physical examination;

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

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

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

71 Section 3. Section **26-45-103** is enacted to read:

72 **26-45-103. Restrictions on employers.**

73 (1) Except as provided in Subsection (2), an employer, as defined in Section 34A-2-103,
74 may not in connection with a hiring, promotion, retention, or other related decision:

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

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

79 (c) request or require an individual or his blood relative to submit to a genetic test; and

80 (d) inquire into or otherwise take into consideration the fact that an individual or his blood
81 relative has taken or refused to take a genetic test.

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

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

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

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

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

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

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

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

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

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

104 Section 4. Section **26-45-104** is enacted to read:

105 **26-45-104. Restrictions on health insurers.**

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

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

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

115 (c) request or require an asymptomatic individual or his blood relative to submit to a
116 genetic test; and

117 (d) inquire into or otherwise take into consideration the fact that an asymptomatic
118 individual or his blood relative has taken or refused to take a genetic test.

119 (2) An insurer offering health care insurance:

120 (a) may request ~~h~~ **[and obtain]** ~~h~~ information regarding the necessity of a genetic test, but
120a not

121 the results of the test, if a claim for payment for the test has been made against an individual's
 122 health insurance policy;

123 (b) may request ~~h [-and obtain] h~~ that portion of private genetic information that is
 123a necessary to

124 determine the insurer's obligation to pay for health care services where:

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

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

129 (c) may only store information obtained under this Subsection (2) ~~h [until the insurer's~~
 130 ~~obligation to pay for a genetic test or health care services has been fully resolved] IN ACCORDANCE~~
 130a ~~WITH THE PROVISIONS OF THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF~~
 130b ~~1996 h ; and~~

131 (d) may only use or otherwise disclose the information obtained under this Subsection (2)
 132 in connection with a proceeding to determine the obligation of an insurer to pay for a genetic test
 133 or health care services, provided that ~~h [;] , IN ACCORDANCE WITH THE PROVISIONS OF THE~~
 133a ~~HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996, THE INSURER MAKES A~~
 133b ~~REASONABLE EFFORT TO LIMIT DISCLOSURE TO THE MINIMUM NECESSARY TO CARRY OUT THE~~
 133c ~~PURPOSES OF THE DISCLOSURE. h~~

134 ~~h [(i) the disclosure of the information is limited to those persons who are direct participants~~
 135 ~~in the proceeding with a legitimate need to know the information;~~

136 ~~—— (ii) the disclosure does not include disclosure of payment for a genetic test to a shared~~
 137 ~~insurance industry database; and~~

138 ~~—— (iii) reasonable measures have been taken to limit disclosure for the protection of the~~
 139 ~~individual.] h~~

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

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

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

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

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

150 (4) Nothing in this section may be construed as restricting the ability of an insurer to use
151 information other than private genetic information to take into account the health status of an

152 individual, group, or population in determining premiums or making other underwriting decisions.

153 (5) Nothing in this section may be construed as requiring an insurer to pay for genetic
 154 testing.

155 (6) Information maintained by an insurer about an individual under this section may be
 156 rediscovered:

157 (a) ~~h~~ [except as prohibited by Subsection (2)(d)(ii);] ~~h~~ to protect the interests of the insurer in
 158 detecting, prosecuting, or taking legal action against criminal activity, fraud, material
 159 misrepresentations, and material omissions;

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

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

163 Section 5. Section **26-45-105** is enacted to read:

164 **26-45-105. Private right of action.**

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

167 (2) Any ~~h~~ [person] **INSURANCE COMPANY OR EMPLOYER** ~~h~~ who violates the legal rights
 167a of an individual arising from this chapter shall

168 be liable to the individual for each separate violation in an amount equal to:

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

170 (b) (i) \$100,000 if the violation is the result of an intentional and wilful act; or

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

172 (c) reasonable attorneys' fees.

173 Section 6. Section **26-45-106** is enacted to read:

174 **26-45-106. Enforcement.**

175 (1) Whenever the attorney general has reason to believe that any person is using or is about
 176 to use any method, act, or practice in violation of the provisions of this chapter, and that
 177 proceedings would be in the public interest, the attorney general may bring an action against the
 178 person to restrain or enjoin the use of such method, act, or practice.

179 (2) In addition to restraining or enjoining the use of a method, act, or practice, the court
 180 may, after June 30, 2003, require the payment of:

181 (a) a civil fine of not more than \$25,000 for each separate intentional violation; and

182 (b) reasonable costs of investigation and litigation, including reasonable attorneys' fees.

183 Section 7. Section 31A-22-1601 is enacted to read:

184 **Part 16. Genetic Testing Restrictions on Insurers**

185 **31A-22-1601. Title.**

186 This part is known as the "Genetic Testing Restrictions on Insurers Act."

187 Section 8. Section 31A-22-1602 is enacted to read:

188 **31A-22-1602. Genetic testing restrictions.**

189 With respect to matters related to genetic testing and private genetic information, an insurer
190 shall comply with Section 26-45-104 and the other applicable provisions of Title 26, Chapter 45,
191 Genetic Testing Privacy Act.

192 Section 9. Section 34A-11-101 is enacted to read:

193 **CHAPTER 11. GENETIC TESTING RESTRICTIONS ON EMPLOYERS ACT**

194 **34A-11-101. Title.**

195 This chapter is known as the "Genetic Testing Restrictions on Employers Act."

196 Section 10. Section 34A-11-102 is enacted to read:

197 **34A-11-102. Restrictions on employers.**

198 With respect to matters related to genetic testing and private genetic information, an
199 employer shall comply with Section 26-45-103 and the other applicable provisions of Title 26,
200 Chapter 45, Genetic Testing Privacy Act.

201 Section 11. **Effective date.**

202 This act takes effect on January 1, 2003.

Legislative Review Note
as of 11-20-01 8:32 AM

A limited legal review of this legislation raises no obvious constitutional or statutory concerns.

Office of Legislative Research and General Counsel

Committee Note

The Health and Human Services Interim Committee recommended this bill.