

Representative Nora B. Stephens proposes to substitute the following bill:

GENETIC TESTING PRIVACY ACT

1999 GENERAL SESSION

STATE OF UTAH

Sponsor: Nora B. Stephens

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5 AN ACT RELATING TO HEALTH; ENACTING THE GENETIC TESTING PRIVACY ACT;
6 DEFINING TERMS; REQUIRING VERBAL INFORMED CONSENT PURSUANT TO AN
7 INSTITUTION'S WRITTEN PROTOCOL PRIOR TO COLLECTING A DNA SAMPLE FOR
8 GENETIC ANALYSIS; REQUIRING WRITTEN CONSENT PURSUANT TO AN
9 INSTITUTION'S WRITTEN PROTOCOL TO DISCLOSE PRIVATE GENETIC
10 INFORMATION TO A THIRD PARTY; PLACING RESTRICTIONS ON EMPLOYERS AND
11 INSURERS WITH LIMITED EXCEPTIONS; ESTABLISHING EXCEPTIONS TO THE
12 REQUIREMENT OF INFORMED CONSENT; PERMITTING COMPELLED DISCLOSURE
13 OF PRIVATE GENETIC INFORMATION IN LIMITED CIRCUMSTANCES; PROVIDING A
14 PRIVATE RIGHT OF ACTION FOR VIOLATIONS AFTER JUNE 2000; AUTHORIZING THE
15 ATTORNEY GENERAL TO ENFORCE THE ACT; AND PROVIDING AN EFFECTIVE
16 DATE.

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

18 AMENDS:

19 **63-2-202**, as last amended by Chapter 312, Laws of Utah 1994

20 **63-2-302**, as last amended by Chapter 303, Laws of Utah 1998

21 ENACTS:

22 **26-44-101**, Utah Code Annotated 1953

23 **26-44-102**, Utah Code Annotated 1953

24 **26-44-103**, Utah Code Annotated 1953

25 **26-44-104**, Utah Code Annotated 1953

- 26 **26-44-105**, Utah Code Annotated 1953
- 27 **26-44-106**, Utah Code Annotated 1953
- 28 **26-44-107**, Utah Code Annotated 1953
- 29 **26-44-108**, Utah Code Annotated 1953
- 30 **26-44-109**, Utah Code Annotated 1953
- 31 **26-44-110**, Utah Code Annotated 1953
- 32 **26-44-111**, Utah Code Annotated 1953
- 33 **31A-22-1601**, Utah Code Annotated 1953
- 34 **31A-22-1602**, Utah Code Annotated 1953
- 35 **34A-9-101**, Utah Code Annotated 1953
- 36 **34A-9-102**, Utah Code Annotated 1953

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

38 Section 1. Section **26-44-101** is enacted to read:

39 **CHAPTER 44. GENETIC TESTING PRIVACY ACT**

40 **26-44-101. Title.**

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

42 Section 2. Section **26-44-102** is enacted to read:

43 **26-44-102. Definitions.**

44 As used in this chapter:

45 (1) "Blood relative" means a person's biologically related:

46 (a) parent;

47 (b) grandparent;

48 (c) child;

49 (d) grandchild;

50 (e) sibling;

51 (f) uncle;

52 (g) aunt;

53 (h) nephew;

54 (i) niece; or

55 (j) first cousin.

56 (2) "Compulsory disclosure" means any disclosure of private genetic information

57 mandated or required by federal law, state law, or Section 26-44-109.

58 (3) "Disclose" or "disclosure" means to convey or to provide access to private genetic
59 information to a person other than the individual.

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

63 (5) "DNA sample" means any human biological specimen from which DNA can be
64 extracted, or DNA extracted from such specimen.

65 (6) "DNA typing" means a scientifically reliable method for characterizing and comparing
66 sequences of DNA, and applying a statistical analysis of population frequency to determine that
67 if the DNA sequences match, the probability that the match occurs by chance.

68 (7) (a) "Genetic analysis" or "genetic test" means the testing or analysis of an identifiable
69 individual's DNA that results in information that is derived from the presence, absence, alteration,
70 or mutation of an inherited gene or genes, or the presence or absence of a specific DNA marker
71 or markers.

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

73 (i) a routine physical examination;

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

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

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

78 (8) (a) "Individual" means the person from whose body the DNA sample originated unless
79 Subsection (b) or (c) applies.

80 (b) In the event that the person from whose body the DNA sample originated is a minor
81 or an incompetent person, "individual" means the person with the legal authority to make health
82 care decisions on behalf of the minor or incompetent person.

83 (c) In the event that the person from whose body the DNA sample originated is deceased,
84 "individual" means, in the following order of priority, the deceased person's:

85 (i) estate administrator or executor;

86 (ii) legal guardian;

87 (iii) spouse;

88 (iv) parent; or

89 (v) child 18 years of age or older.

90 (9) "Individual identifier" means a name, address, Social Security number, health insurance
91 identification number, or similar information by which the identity of an individual can be
92 determined with reasonable accuracy. The term does not include information that has been
93 anonymized through encryption or encoding.

94 (10) "Institutional Review Board" means a board established in accordance with 45 CFR
95 46.102(g)(1992) as such regulation may be amended.

96 (11) "Legal rights" means any statutory or contractual right that arises as a result of or in
97 connection with the provisions of this chapter.

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

99 (13) (a) "Private genetic information" means any information about an identifiable
100 individual that is derived from the presence, absence, alteration, or mutation of an inherited gene
101 or genes, or the presence or absence of a specific DNA marker or markers, and which has been
102 obtained:

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

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

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

107 (i) a routine physical examination;

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

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

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

112 (14) "Verbal informed consent" means a face-to-face exchange in which an individual is
113 informed of the significance of undergoing a genetic test and the unique health information that
114 may result from such a test in a manner that complies with written protocols for verbal informed
115 consent for genetic testing privacy adopted by:

116 (a) the clinical institution under whose direction informed consent is being sought; or

117 (b) the research institution under whose direction informed consent is being sought,
118 provided that the written protocols have been approved by an institutional review board.

119 (15) "Prior written authorization" means a document signed and dated by an individual
120 authorizing the disclosure of private genetic information to a person or class of persons after being
121 informed of the significance of the authorization in a manner that complies with written protocols
122 for prior written authorization for disclosure of private genetic information adopted by:

123 (a) the institution in possession of the individual's private genetic information; and

124 (b) an institutional review board, if the institution in possession of the individual's private
125 genetic information conducts research.

126 Section 3. Section **26-44-103** is enacted to read:

127 **26-44-103. DNA samples collected before or after July 1, 1999.**

128 Except as provided in Section 26-44-108, an individually identifiable DNA sample
129 collected in this state:

130 (1) for genetic analysis on or after July 1, 1999, may only be collected, analyzed, stored,
131 and used for research or other purposes to the extent expressly permitted by and in strict
132 accordance with informed consent obtained in compliance with the requirements of Section
133 26-44-104;

134 (2) before July 1, 1999, may be subject to genetic analysis for clinical purposes without
135 complying with the provisions of Section 26-44-104; and

136 (3) before July 1, 1999, may be subject to genetic analysis for research purposes:

137 (a) in accordance with the specific purpose for which the sample was originally collected;

138 (b) after the sample has been permanently anonymized through the removal and
139 destruction of individual identifiers; or

140 (c) in connection with a research protocol approved by an institutional review board and:

141 (i) the informed consent requirements of Section 26-44-104 are met; or

142 (ii) a person who serves as a custodian of records and is not directly involved in research
143 or genetic analysis:

144 (A) directs the removal of all individually identifying information from the DNA sample
145 before the sample is analyzed in connection with the approved research protocol;

146 (B) if the identifying information is not destroyed, maintains the confidentiality of
147 individually identifying information and stores the information in a manner in which only the
148 custodian of records and his direct subordinates have access to the information; and

149 (C) only uses stored individually identifying information if:

150 (I) the use is necessary to further a legitimate research purpose which is approved by an
151 institutional review board;

152 (II) the confidentiality of the information can be maintained in accordance with Subsection
153 (3)(c)(ii)(B); and

154 (III) the disclosure of individually identifying information is limited to the individual, the
155 individual's next of kin, and the individual's health care providers.

156 Section 4. Section **26-44-104** is enacted to read:

157 **26-44-104. Informed consent for genetic testing.**

158 (1) Except as provided in Section 26-44-108, no person may collect or cause to be
159 collected an individually identifiable DNA sample in this state for genetic analysis without:

160 (a) obtaining verbal informed consent; and

161 (b) informing the individual of the existence of the institution's written protocol for genetic
162 testing privacy.

163 (2) A person may not perform a genetic test on an individually identifiable DNA sample
164 if that person has actual knowledge that the individual:

165 (a) was in Utah at the time the sample was collected; and

166 (b) did not give informed consent in the manner required by Subsection (1).

167 (3) (a) Insurers and employers are prohibited from seeking an individual's informed
168 consent for genetic testing.

169 (b) Notwithstanding Subsection (3)(a), a health care provider who is employed by an
170 insurer to provide direct health care services to insureds may seek an individual's informed consent
171 for genetic testing as long as:

172 (i) the request is for a legitimate medical purpose; and

173 (ii) the insurer does not have access to the resulting private genetic information, except to
174 the extent permitted in Subsection 26-44-107(2).

175 (4) An individual shall be given a copy of an institution's written protocol for genetic
176 testing privacy upon request.

177 Section 5. Section **26-44-105** is enacted to read:

178 **26-44-105. Disclosure of private genetic information.**

179 (1) Except as provided in Sections 26-44-108 and 26-44-109, no person who, in the
180 ordinary course of business, practice of a profession, or rendering of a service, creates, stores,

181 receives, or furnishes private genetic information, may disclose private genetic information to any
182 other person without:

183 (a) the prior written authorization of the individual; and

184 (b) informing the individual of the existence of the institution's written protocol for
185 disclosure of private genetic information.

186 (2) A copy of the written authorization shall be provided to the individual. A copy of the
187 institution's written protocol for disclosure of private genetic information shall be given to the
188 individual upon request.

189 (3) An individual may revoke or amend the authorization at any time by contacting the
190 person to whom authorization was given.

191 (4) An individual may not maintain an action against a person for disclosure of private
192 genetic information made in good faith reliance on a valid written authorization if the person had
193 no notice of the revocation of the authorization at the time the disclosure was made.

194 (5) Each disclosure made pursuant to a written authorization described in Subsection (1)
195 shall be accompanied by the following written statement: "This information has been disclosed to
196 you from private records protected under the Genetic Testing Privacy Act and any further
197 disclosure of the information without specific authorization from the individual is prohibited."

198 (6) A general authorization for the release of medical records or medical information may
199 not be used as a written authorization for the disclosure of private genetic information.

200 (7) An insurer may only use this section to access an individual's private genetic
201 information:

202 (a) to determine the insurer's obligation to pay for a genetic test or health care services
203 under Subsection 26-44-107(2); or

204 (b) as permitted in Subsection 26-44-107(4)(b).

205 (8) An employer may not use this section to access an individual's private genetic
206 information unless the individual has knowingly and voluntarily waived his right to have a court
207 or administrative law judge make a determination as to whether the disclosure of private genetic
208 information should be compelled under Section 26-44-108.

209 (9) Private genetic information in the possession of an employer or insurer may not be
210 disclosed by means of a written authorization to any person other than:

211 (a) the individual; and

212 (b) the individual's health care provider.

213 Section 6. Section **26-44-106** is enacted to read:

214 **26-44-106. Restrictions on employers.**

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

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

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

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

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

224 (2) (a) Notwithstanding Subsection (1), an employer may seek an order compelling the
225 disclosure of private genetic information held by an individual or third party pursuant to Section
226 26-44-109 in connection with:

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

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

232 (b) An order compelling the disclosure of private genetic information may only be entered
233 if the requirements of Subsections 26-44-109(4) and (5) have been met.

234 Section 7. Section **26-44-107** is enacted to read:

235 **26-44-107. Restrictions on insurers.**

236 (1) Except as provided in Subsections (2) and (4), an insurer may not in connection with
237 the offer or renewal of an insurance product or in the determination of premiums, coverage,
238 renewal, cancellation, or any other underwriting decision that pertains directly to the individual
239 or any group of which the individual is a member that purchases insurance jointly:

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

242 (b) request or require an individual to consent to a release for the purpose of accessing

243 private genetic information about the individual;

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

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

247 (2) With respect to health insurance, as defined in Subsection 31A-1-301(35), an insurer:

248 (a) may request and obtain information regarding the necessity of a genetic test, but not
249 the results of the test, if a claim for payment for the test has been made against an individual's
250 health insurance policy;

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

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

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

257 (c) may only store information obtained under this Subsection (2) until the insurer's
258 obligation to pay for a genetic test or health care services has been fully resolved; and

259 (d) may only use or otherwise disclose the information in connection with a proceeding
260 to determine the obligation of an insurer to pay for a genetic test or health care services, provided
261 that:

262 (i) the disclosure of the information is limited to those persons who are direct participants
263 in the proceeding with a legitimate need to know the information; and

264 (ii) reasonable measures have been taken to limit disclosure for the protection of the
265 individual.

266 (3) (a) An insurer may, to the extent permitted by Subsection (2), seek an order compelling
267 the disclosure of private genetic information held by an individual or third party pursuant to
268 Section 26-44-109.

269 (b) An action brought in accordance with Subsection (2) shall be presumed to meet the
270 finding requirement of Subsection 26-44-109(4).

271 (c) An order authorizing the disclosure of private genetic information shall comply with
272 Subsection 26-44-109(5).

273 (4) With respect to insurance other than health insurance, an insurer may in connection

274 with the offer or renewal of an insurance policy or in the determination of premiums, coverage,
275 or renewal:

276 (a) inquire into whether the individual or any other blood relative has undergone a genetic
277 test and what the results of the test, if known, were;

278 (b) if the individual has undergone a genetic test, is aware of the results of that test, and
279 requests more than the average amount of coverage for a person of similar age and income, request
280 the individual to release his private genetic information to the insurer;

281 (c) store information obtained under Subsection (4)(b) for 60 days before it must be
282 destroyed; and

283 (d) record the disposition of an application based on information obtained under
284 Subsection (4)(b) and the risk associated with the individual as long as there is no mention of a
285 specific illness, disease, or other health condition.

286 (5) Nothing in Subsection (4) may be construed as:

287 (a) permitting an insurer to disclose private genetic information or the insurer's disposition
288 of an insurance application based on private genetic information to a person other than the
289 individual, except as provided in Subsection (7); or

290 (b) restricting the right of an insurer to deny a claim in accordance with the terms of an
291 insurance policy or otherwise seeking relief if information properly requested under Subsection
292 (4)(a) was knowingly withheld.

293 (6) Outside of private genetic information, nothing in this section may be construed as
294 restricting the ability of an insurer to take into account the health status of an individual, group,
295 or population in determining premiums or making other underwriting decisions.

296 (7) Information maintained by an insurer about an individual under this section may be
297 redisclosed:

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

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

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

303 Section 8. Section **26-44-108** is enacted to read:

304 **26-44-108. Exceptions to informed consent.**

305 (1) Notwithstanding any other provision in this chapter, a person may provide access to
306 an individually identifiable DNA sample, or to data derived from DNA typing, to assist in the
307 identification of a dead body, provided that the analysis of any sample so provided and the analysis
308 of any DNA sample from the dead body is limited to that which is necessary to determine the
309 identity of the dead body.

310 (2) Nothing in this chapter may be construed to affect criminal investigations, criminal
311 proceedings, or the authority of law enforcement agencies under Title 53, Chapter 5, Part 10,
312 Criminal Investigations and Technical Services Division, in collecting, storing, testing, typing, and
313 controlling access to DNA samples in the course of conducting criminal investigations.

314 (3) (a) With the exception of Sections 26-44-106 and 26-44-107, which apply to insurers
315 and employers, nothing in this chapter may be construed to prohibit the collection or analysis of
316 an individually identifiable DNA sample pursuant to Title 62A, Chapter 11, Recovery Services;
317 Title 78, Chapter 45a, Uniform Act on Paternity; or Rule 35 of the Utah Rules of Civil Procedure
318 if the provisions of this Subsection (3) have been met.

319 (b) An order or agency request under Subsection (3)(a) may only be entered upon a finding
320 that:

321 (i) the genetic condition of the individual has been placed at issue;

322 (ii) other ways of obtaining the private information are not available or would not be
323 effective; and

324 (iii) there is a compelling need for the private genetic information which substantially
325 outweighs the potential harm to the privacy interests of the individual.

326 (c) An order or agency request under Subsection (3)(a) shall specify:

327 (i) the manner of collection of the DNA sample;

328 (ii) the person or persons authorized to collect and analyze the DNA sample;

329 (iii) the purpose of the genetic analysis;

330 (iv) that the genetic analysis is limited to that which is necessary to fulfill the purpose of
331 the order or request;

332 (v) that the sample may only be stored until the matter underlying the order or agency
333 request has been resolved and the time for appeal has lapsed;

334 (vi) those persons to whom disclosure of the resulting private genetic information may be
335 made because of a compelling need to know such information; and

336 (vii) such other measures as may be necessary to limit disclosure of the resulting private
337 genetic information for the protection of the individual.

338 (d) A paternity action brought under Subsection (3)(a) shall be presumed to meet the
339 finding requirement of Subsection (3)(b).

340 Section 9. Section **26-44-109** is enacted to read:

341 **26-44-109. Compulsory disclosure of private genetic information.**

342 (1) No person, including an individual, who maintains private genetic information may be
343 compelled to disclose such information pursuant to a request for compulsory disclosure in any
344 judicial, legislative, or administrative proceeding unless:

345 (a) the person maintaining the genetic information has received the authorization of the
346 individual to release the information in response to the request for compulsory disclosure;

347 (b) the individual is a party to or the subject of the proceeding, the private genetic
348 information is at issue, and the requirements of Section 26-44-106 and 26-44-107, if applicable,
349 have been met; or

350 (c) the genetic information is for use in a law enforcement proceeding or investigation in
351 which the person maintaining the information is the subject or a party.

352 (2) (a) A person requesting compulsory disclosure pursuant to Subsection (1)(b) or (c)
353 shall serve upon the person maintaining the genetic information and upon the individual:

354 (i) a copy of the request at least ten days prior to the date on which the compulsory
355 disclosure is requested; and

356 (ii) a statement of the right of the individual or person maintaining the genetic information
357 to have any objections to compulsory disclosure heard by the court, legislature, or administrative
358 agency prior to the issuance of a compulsory disclosure order, and the procedure to be followed
359 to have any such objections heard.

360 (b) Service under Subsection (2)(a) may be sent by certified mail, return receipt requested,
361 or hand-delivered.

362 (3) Service of a compulsory disclosure request upon a person maintaining private genetic
363 information shall be accompanied by a written certification, signed by the person seeking to obtain
364 the private genetic information or his authorized representative:

365 (a) identifying at least one subsection of Section (1) in justification of compulsory
366 disclosure; and

- 367 (b) indicating that the notice requirement of Subsection (2)(a) has been met.
- 368 (4) An order under this section may only be entered upon a finding that:
- 369 (a) other ways of obtaining the private information are not available or would not be
- 370 effective; and
- 371 (b) there is a compelling need for the private genetic information which substantially
- 372 outweighs the potential harm to the privacy interests of the individual.
- 373 (5) An order under this section which authorizes the disclosure of private genetic
- 374 information shall:
- 375 (a) limit disclosure to those parts of the record containing such information as is essential
- 376 to fulfill the objective of the order;
- 377 (b) limit disclosure to those persons whose need for the information is the basis of the
- 378 order; and
- 379 (c) include such other measures as may be necessary to limit disclosure for the protection
- 380 of the individual.

381 Section 10. Section **26-44-110** is enacted to read:

382 **26-44-110. Private right of action.**

383 (1) An individual whose legal rights arising under this chapter have been violated after

384 June 30, 2000, may recover damages and be granted equitable relief in a civil action.

385 (2) Any person who unintentionally violates the legal rights of an individual arising from

386 this chapter shall be liable to the individual for each separate violation in an amount equal to:

- 387 (a) actual damages sustained as a result of the violation or \$5,000, whichever is greater;
- 388 (b) treble damages, if the violation resulted in profit or monetary gain; and
- 389 (c) reasonable attorneys' fees and costs.

390 (3) Any person who intentionally induces a person to violate the legal rights of an

391 individual arising from this chapter, or who, himself, intentionally violates the legal rights of an

392 individual arising from this chapter shall be liable to the individual for each separate violation in

393 an amount equal to:

- 394 (a) actual damages sustained as a result of the violation or \$15,000, whichever is greater;
- 395 (b) punitive damages as the court may allow; and
- 396 (c) reasonable attorneys' fees and costs.

397 Section 11. Section **26-44-111** is enacted to read:

398 **26-44-111. Enforcement.**

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

403 (2) In addition to restraining or enjoining the use of a method, act, or practice, the court
404 may, after June 30, 2000, require the payment of:

405 (a) a civil fine of not more than:

406 (i) \$10,000 for each separate unintentional violation; and

407 (ii) \$30,000 for each separate intentional violation; and

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

409 Section 12. Section **31A-22-1601** is enacted to read:

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

411 **31A-22-1601. Title.**

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

413 Section 13. Section **31A-22-1602** is enacted to read:

414 **31A-22-1602. Genetic testing restrictions.**

415 With respect to matters related to genetic testing and private genetic information, an insurer
416 shall comply with Section 26-44-107 and the other applicable provisions of Title 26, Chapter 44,
417 Genetic Testing Privacy Act.

418 Section 14. Section **34A-9-101** is enacted to read:

419 **CHAPTER 9. GENETIC TESTING RESTRICTIONS ON EMPLOYERS ACT**

420 **34A-9-101. Title.**

421 This part is known as the "Genetic Testing Restrictions on Employers Act."

422 Section 15. Section **34A-9-102** is enacted to read:

423 **34A-9-102. Restrictions on employers.**

424 With respect to matters related to genetic testing and private genetic information, an
425 employer shall comply with Section 26-44-106 and the other applicable provisions of Title 26,
426 Chapter 44, Genetic Testing Privacy Act.

427 Section 16. Section **63-2-202** is amended to read:

428 **63-2-202. Access to private, controlled, and protected documents.**

- 429 (1) Upon request, a governmental entity shall disclose a private record to:
- 430 (a) the subject of the record;
- 431 (b) the parent or legal guardian of an unemancipated minor who is the subject of the
- 432 record;
- 433 (c) the legal guardian of a legally incapacitated individual who is the subject of the record;
- 434 (d) any other individual who:
- 435 (i) has a power of attorney from the subject of the record;
- 436 (ii) submits a notarized release from the subject of the record or his legal representative
- 437 dated no more than 90 days before the date the request is made; or
- 438 (iii) if the record is a medical record described in Subsection 63-2-302(1)(b), is a health
- 439 care provider, as defined in Subsection 26-33a-102(7), if releasing the record or information in the
- 440 record is consistent with normal professional practice and medical ethics and Title 26, Chapter 44,
- 441 Genetic Testing Privacy Act; or
- 442 (e) any person to whom the record must be provided pursuant to court order as provided
- 443 in Subsection (7) or a legislative subpoena as provided in Title 36, Chapter 14, Legislative
- 444 Subpoena Powers.
- 445 (2) (a) Upon request, a governmental entity shall disclose a controlled record to:
- 446 (i) a physician, psychologist, certified social worker, insurance provider or agent, or a
- 447 government public health agency upon submission of a release from the subject of the record that
- 448 is dated no more than 90 days prior to the date the request is made and a signed acknowledgment
- 449 of the terms of disclosure of controlled information as provided by Subsection (2)(b); and
- 450 (ii) any person to whom the record must be disclosed pursuant to court order as provided
- 451 in Subsection (7) or a legislative subpoena as provided in Title 36, Chapter 14.
- 452 (b) A person who receives a record from a governmental entity in accordance with
- 453 Subsection (2)(a)(i) may not disclose controlled information from that record to any person,
- 454 including the subject of the record.
- 455 (3) If there is more than one subject of a private or controlled record, the portion of the
- 456 record that pertains to another subject shall be segregated from the portion that the requester is
- 457 entitled to inspect.
- 458 (4) Upon request, a governmental entity shall disclose a protected record to:
- 459 (a) the person who submitted the record;

460 (b) any other individual who:

461 (i) has a power of attorney from all persons, governmental entities, or political
462 subdivisions whose interests were sought to be protected by the protected classification; or

463 (ii) submits a notarized release from all persons, governmental entities, or political
464 subdivisions whose interests were sought to be protected by the protected classification or from
465 their legal representatives dated no more than 90 days prior to the date the request is made; or

466 (c) any person to whom the record must be provided pursuant to a court order as provided
467 in Subsection (7) or a legislative subpoena as provided in Title 36, Chapter 14.

468 (5) A governmental entity may disclose a private, controlled, or protected record to another
469 governmental entity, political subdivision, another state, the United States, or a foreign government
470 only as provided by Section 63-2-206.

471 (6) Before releasing a private, controlled, or protected record, the governmental entity shall
472 obtain evidence of the requester's identity.

473 (7) A governmental entity shall disclose a record pursuant to the terms of a court order
474 signed by a judge from a court of competent jurisdiction, provided that:

475 (a) the record deals with a matter in controversy over which the court has jurisdiction;

476 (b) the court has considered the merits of the request for access to the record; and

477 (c) the court has considered and, where appropriate, limited the requester's use and further
478 disclosure of the record in order to protect privacy interests in the case of private or controlled
479 records, business confidentiality interests in the case of records protected under Subsections
480 63-2-304(1) and (2), and privacy interests or the public interest in the case of other protected
481 records;

482 (d) to the extent the record is properly classified private, controlled, or protected, the
483 interests favoring access, considering limitations thereon, outweigh the interests favoring
484 restriction of access; and

485 (e) where access is restricted by a rule, statute, or regulation referred to in Subsection
486 63-2-201(3)(b), the court has authority independent of this chapter to order disclosure.

487 (8) (a) A governmental entity may disclose or authorize disclosure of private or controlled
488 records for research purposes if the governmental entity:

489 (i) determines that the research purpose cannot reasonably be accomplished without use
490 or disclosure of the information to the researcher in individually identifiable form;

491 (ii) determines that the proposed research is bona fide, and that the value of the research
492 outweighs the infringement upon personal privacy;

493 (iii) requires the researcher to assure the integrity, confidentiality, and security of the
494 records and requires the removal or destruction of the individual identifiers associated with the
495 records as soon as the purpose of the research project has been accomplished;

496 (iv) prohibits the researcher from disclosing the record in individually identifiable form,
497 except as provided in Subsection (8)(b), or from using the record for purposes other than the
498 research approved by the governmental entity; [and]

499 (v) secures from the researcher a written statement of his understanding of and agreement
500 to the conditions of this subsection and his understanding that violation of the terms of this
501 subsection may subject him to criminal prosecution under Section 63-2-801[-]; and

502 (vi) requires that the researcher complies with the provisions of Title 26, Chapter 44,
503 Genetic Testing Privacy Act, if the research involves genetic information.

504 (b) A researcher may disclose a record in individually identifiable form if the record is
505 disclosed for the purpose of auditing or evaluating the research program and no subsequent use or
506 disclosure of the record in individually identifiable form will be made by the auditor or evaluator
507 except as provided by this section.

508 (c) A governmental entity may require indemnification as a condition of permitting
509 research under this subsection.

510 (9) (a) Under Subsections 63-2-201(5)(b) and 63-2-401(6) a governmental entity may
511 disclose records that are private under Section 63-2-302, or protected under Section 63-2-304 to
512 persons other than those specified in this section.

513 (b) Under Subsection 63-2-403(11)(b) the Records Committee may require the disclosure
514 of records that are private under Section 63-2-302, controlled under Section 63-2-303, or protected
515 under Section 63-2-304 to persons other than those specified in this section.

516 (c) Under Subsection 63-2-404(8) the court may require the disclosure of records that are
517 private under Section 63-2-302, controlled under Section 63-2-303, or protected under Section
518 63-2-304 to persons other than those specified in this section.

519 Section 17. Section **63-2-302** is amended to read:

520 **63-2-302. Private records.**

521 (1) The following records are private:

522 (a) records concerning an individual's eligibility for unemployment insurance benefits,
523 social services, welfare benefits, or the determination of benefit levels;

524 (b) records containing data on individuals describing medical history, diagnosis, condition,
525 treatment, evaluation, private genetic information, as defined in Section 26-44-102, or similar
526 medical data;

527 (c) records of publicly funded libraries that when examined alone or with other records
528 identify a patron;

529 (d) records received or generated for a Senate or House Ethics Committee concerning any
530 alleged violation of the rules on legislative ethics, prior to the meeting, and after the meeting, if
531 the ethics committee meeting was closed to the public;

532 (e) records received or generated for a Senate confirmation committee concerning
533 character, professional competence, or physical or mental health of an individual:

534 (i) if prior to the meeting, the chair of the committee determines release of the records:

535 (A) reasonably could be expected to interfere with the investigation undertaken by the
536 committee; or

537 (B) would create a danger of depriving a person of a right to a fair proceeding or impartial
538 hearing;

539 (ii) after the meeting, if the meeting was closed to the public;

540 (f) records concerning a current or former employee of, or applicant for employment with,
541 a governmental entity that would disclose that individual's home address, home telephone number,
542 social security number, insurance coverage, marital status, or payroll deductions; and

543 (g) that part of a record indicating a person's social security number if provided under
544 Section 31A-23-202, 31A-26-202, 58-1-301, 61-1-4, or 61-2-6.

545 (2) The following records are private if properly classified by a governmental entity:

546 (a) records concerning a current or former employee of, or applicant for employment with
547 a governmental entity, including performance evaluations and personal status information such as
548 race, religion, or disabilities, but not including records that are public under Subsection
549 63-2-301(1)(b) or 63-2-301(2)(o), or private under Subsection 63-2-302(1)(b);

550 (b) records describing an individual's finances, except that the following are public:

551 (i) records described in Subsection 63-2-301(1);

552 (ii) information provided to the governmental entity for the purpose of complying with a

553 financial assurance requirement; or
554 (iii) records that must be disclosed in accordance with another statute;
555 (c) records of independent state agencies if the disclosure of those records would conflict
556 with the fiduciary obligations of the agency;
557 (d) other records containing data on individuals the disclosure of which constitutes a
558 clearly unwarranted invasion of personal privacy; and
559 (e) records provided by the United States or by a government entity outside the state that
560 are given with the requirement that the records be managed as private records, if the providing
561 entity states in writing that the record would not be subject to public disclosure if retained by it.
562 (3) (a) As used in this Subsection (3), "medical records" means medical reports, records,
563 statements, history, diagnosis, condition, treatment, and evaluation.
564 (b) Medical records in the possession of the University of Utah Hospital, its clinics,
565 doctors, or affiliated entities are not private records or controlled records under Section 63-2-303
566 when the records are sought:
567 (i) in connection with any legal or administrative proceeding in which the patient's
568 physical, mental, or emotional condition is an element of any claim or defense; or
569 (ii) after a patient's death, in any legal or administrative proceeding in which any party
570 relies upon the condition as an element of the claim or defense.
571 (c) Medical records are subject to production in a legal or administrative proceeding
572 according to state or federal statutes or rules of procedure and evidence as if the medical records
573 were in the possession of a nongovernmental medical care provider.
574 Section 18. **Effective date.**
575 This act takes effect on July 1, 1999.