

**GENETIC PRIVACY AND DISCRIMINATION**

2002 GENERAL SESSION

STATE OF UTAH

**Sponsor: Paul Ray**

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

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

ENACTS:

- 26-45-101, Utah Code Annotated 1953
- 26-45-102, Utah Code Annotated 1953
- 26-45-103, Utah Code Annotated 1953
- 26-45-104, Utah Code Annotated 1953
- 26-45-105, Utah Code Annotated 1953
- 26-45-106, Utah Code Annotated 1953
- 31A-22-1601, Utah Code Annotated 1953
- 31A-22-1602, Utah Code Annotated 1953
- 34A-11-101, Utah Code Annotated 1953
- 34A-11-102, Utah Code Annotated 1953

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

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

**CHAPTER 45. GENETIC TESTING PRIVACY ACT**

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

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

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

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

As used in this chapter:

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

(a) parent;

(b) grandparent;

(c) child;

(d) grandchild;

(e) sibling;

(f) uncle;

(g) aunt;

(h) nephew;

(i) niece; or

(j) first cousin.

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

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

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

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

(i) a routine physical examination;

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

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

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

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

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

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

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

(b) "Private genetic information" does not include information that is derived from:  
(i) a routine physical examination;  
(ii) a routine chemical, blood, or urine analysis;  
(iii) a test to identify the presence of drugs or HIV infection; or  
(iv) a test performed due to the presence of signs, symptoms, or other manifestations of a disease, illness, impairment, or other disorder.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(2) An insurer offering health care insurance:

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

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

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

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

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

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

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

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

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

(ii) limit disclosure to those persons whose need for the information is the basis for the

order; and

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(c) reasonable attorneys' fees.

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

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

(1) Whenever the attorney general has reason to believe that any person is using or is about

to use any method, act, or practice in violation of the provisions of this chapter, and that proceedings would be in the public interest, the attorney general may bring an action against the person to restrain or enjoin the use of such method, act, or practice.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Section 11. **Effective date.**

This act takes effect on January 1, 2003.