Effective 5/3/2023

Part 2
Genetic Testing and Procedure Privacy Act

13-60-203 Definitions.

As used in this part:

(1) "Blood relative" means an individual'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:
- (a) 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; or
- (b) proteins, enzymes, or other molecules associated with a genetic process, which may be modified, replaced in part or whole, superseded, or bypassed in function by a health or medical procedure.

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

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

(5)
- (a) "Genetic analysis" or "genetic test" means the testing, detection, 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.

(6) "Genetic procedure" means any therapy, treatment, or medical procedure that is intended to:
- (a) add, remove, alter, activate, change, or cause mutation in an individual's inherited DNA; or
- (b) replace, supersede, or bypass a normal DNA function.

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

(8)
- (a) "Private genetic information" means any information about an identifiable individual that:
  - (i) is derived from:
    - (A) the presence, absence, alteration, or mutation of an inherited gene or genes; or
    - (B) the presence or absence of a specific DNA marker or markers; and

(ii) has been obtained:
(A) from a genetic test or analysis of the individual's DNA;
(B) from a genetic test or analysis of the DNA of a blood relative of the individual; or
(C) from a genetic procedure.
(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.

Renumbered and Amended by Chapter 327, 2023 General Session

13-60-204 Restrictions on employers.

(1) Except as provided in Subsection (2), an employer 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 the individual's blood relative to submit to:
(i) a genetic test; or
(ii) a genetic procedure; or
(d) inquire into or otherwise take into consideration the fact that an individual or the individual's blood relative has:
(i) taken or refused to take a genetic test; or
(ii) undergone or refused to undergo a genetic procedure.
(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.

Renumbered and Amended by Chapter 327, 2023 General Session

13-60-205 Restrictions on health insurers.

(1) Except as provided in Subsection (2), an insurer offering health care insurance 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 the individual's blood relative to submit to a genetic test;
  (d) inquire into or otherwise take into consideration the fact that an asymptomatic individual or the individual's blood relative has taken or refused to take a genetic test;
  (e) request or require an individual or the individual's blood relative to submit to a genetic procedure; or
  (f) inquire into the results of a genetic procedure that an individual or the individual's blood relative undergoes.
(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 information regarding the necessity of a genetic procedure, including the results of the procedure, if a claim for payment for the procedure has been made against an individual's health insurance policy;
  (c) 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;
  (d) 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
  (e) 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:
(a) requiring an insurer to pay for genetic testing or a genetic procedure; or
(b) prohibiting the use of step-therapy protocols.

(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.

Renumbered and Amended by Chapter 327, 2023 General Session

13-60-206 Private right of action.

(1)
(a) An individual whose legal rights arising under this part have been violated after June 30, 2003, may recover damages and be granted equitable relief in a civil action.
(b) Subsection (1)(a) does not create a legal right prior to the Legislature enacting the right under this part.

(2) Any insurance company or employer who violates the legal rights of an individual arising from this part 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 willful act; or
(ii) punitive damages if the violation is the result of a malicious act; and
(c) reasonable attorneys' fees.

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13-60-207 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 part, 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.

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