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CHAPTER 93.

 PRIVACY OF GENETIC INFORMATION

**SECTION 38‑93‑10.** Definitions.

As used in this chapter:

(1) “Family member” means, with respect to an individual:

(a) a dependent of the individual; and

(b) any other individual who is a first‑degree, second‑degree, third‑degree, or fourth‑degree relative of the individual or his dependent.

(2)(a) “Genetic information” means, with respect to an individual, the:

(i) individual’s genetic tests;

(ii) genetic tests of the individual’s family members; and

(iii) manifestation of a disease or disorder in family members of the individual.

(b) The term includes, with respect to an individual, a request for, or receipt of, genetic services or participation in clinical research which includes genetic services by the individual or a family member of the individual.

(c) A reference to genetic information concerning an individual or family member of an individual includes:

(i) with respect to an individual or family member of an individual who is a pregnant woman, genetic information on any fetus carried by the pregnant woman; or

(ii) with respect to an individual or family member of an individual utilizing an assisted reproductive technology, genetic information of an embryo legally held by the individual or family member.

(d) The term does not include information about the sex or age of an individual.

(3) “Genetic services” means:

(a) a genetic test;

(b) genetic counseling, including obtaining, interpreting, or assessing genetic information; or

(c) genetic education.

(4)(a) “Genetic test” means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations or chromosomal changes.

(b) The term does not include:

(i) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or

(ii) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that reasonably could be detected by a health care professional with appropriate training and expertise in the field of medicine involved.

(5) “Health insurance coverage” or “coverage” means as defined in Sections 38‑71‑670(6) and 38‑71‑840(14).

(6) “Health insurance issuer” or “issuer” means an entity that provides health insurance coverage in this State as defined in Sections 38‑71‑670(7) and 38‑71‑840(16).

(7) “Individual” means an insured, individual enrollee, covered dependent, participant, covered person, beneficiary, eligible employee, dependent of an eligible employee, or applicant for coverage.

(8) “Secretary” means the Secretary of the United States Department of Health and Human Services.

(9) “Underwriting purposes” means:

(a) rules for, or determination of, eligibility including enrollment and continued eligibility for benefits under the policy or coverage;

(b) the computation of premium or contribution amounts under the policy or coverage;

(c) the application of any preexisting condition exclusion under the policy or coverage; and

(d) other activities related to the creation, renewal, or replacement of a policy or contract of health insurance coverage.

**SECTION 38‑93‑20.** Applicability.

This chapter applies to health insurance coverage offered in connection with an individual health plan, a group health plan, or a health benefit plan that is delivered, issued for delivery, or renewed in this State. Producers, agencies, and insurance support organizations are subject to the provisions of this chapter to the extent of their participation in the issue, reissue, or renewal of a policy or contract of health insurance coverage.

**SECTION 38‑93‑30.** Medical coverage and health insurance; restrictions or discrimination on basis of genetic information prohibited.

(A) A health insurance issuer when issuing, renewing, or reissuing a policy or contract of health insurance coverage, on the basis of any genetic information obtained concerning an individual or a family member of the individual or on the individual’s request for genetic services, with respect to the policy or contract, may not:

(1) terminate, restrict, limit, or otherwise apply conditions to coverage of an individual or restrict the sale to an individual;

(2) cancel or refuse to renew the coverage of an individual;

(3) exclude an individual from coverage or establish rules for eligibility, including continued eligibility, of an individual to enroll for coverage;

(4) impose a waiting period before commencement of coverage of an individual;

(5) impose a preexisting condition exclusion;

(6) require inclusion of a rider that excludes coverage for certain benefits or services; or

(7) adjust premium or contribution amounts or establish a differential in premium rates for coverage.

(B)(1) In the case of group health insurance coverage, a health insurance issuer is prohibited from adjusting premium or contribution amounts for the group covered under a policy or contract of group health insurance coverage on the basis of genetic information.

(2) Nothing in item (1) may be construed to limit the ability of an issuer offering group health insurance coverage to increase the premium for an employer based on the manifestation of a disease or disorder in an individual who is enrolled in the policy or contract of coverage. In this case, the manifestation of a disease or disorder in one individual may not be used as genetic information about other group members and to further increase the premium for the employer.

(C) In addition, discrimination must not be made in the fees or commissions of a producer or agency for an enrollment, application, or the renewal of coverage of an individual or group on the basis of an individual’s genetic information.

**SECTION 38‑93‑40.** Confidentiality; disclosure restrictions and exceptions.

(A) All genetic information obtained before or after the effective date of this chapter must be confidential and must not be disclosed to a third party in a manner that allows identification of the individual tested without first obtaining the written informed consent of that individual or a person legally authorized to consent on behalf of the individual, except that genetic information may be disclosed without consent:

(1) as necessary for the purpose of a criminal or death investigation, a criminal or judicial proceeding, an inquest, or a child fatality review, or for purposes of the State DNA Database established by Section 23‑3‑610;

(2) to determine the paternity of a person pursuant to Section 63‑17‑30;

(3) pursuant to an order of a court of competent jurisdiction specifically ordering disclosure of the genetic information;

(4) where genetic information concerning a deceased individual will assist in medical diagnosis of blood relatives of the decedent;

(5) to a law enforcement or other authorized agency for the purpose of identifying a person or a dead body; or

(6) as specifically authorized or required by a state or federal statute.

(B) A health insurance issuer may not require an individual to consent to the disclosure of genetic information to the issuer as a condition for obtaining health insurance coverage.

**SECTION 38‑93‑50.** Informed consent required for genetic test; exceptions.

It is unlawful to perform a genetic test on an individual without first obtaining specific informed consent to the test from the individual, or a person legally authorized to consent on behalf of the individual, unless the test is performed:

(1) by or for a law enforcement agency in a criminal investigation or for the State DNA Database as provided in Sections 23‑3‑620 through 23‑3‑640;

(2) for purposes of identifying a person or a dead body;

(3) to establish paternity as provided by Section 63‑17‑30;

(4) pursuant to a statute or court order specifically requiring that the test be performed; or

(5) for diagnosis or treatment of the individual if performed by a clinical laboratory that has received a specimen referral from the individual’s treating physician or another clinical laboratory. Nothing in this item may be construed so as to waive the requirement that the treating physician obtain specific informed consent in accordance with the provisions of this section.

**SECTION 38‑93‑60.** Health insurance issuer may not request or require an individual or a family member of an individual to undergo a genetic test; exception.

(A) A health insurance issuer may not request or require an individual or a family member of an individual to undergo a genetic test. However, nothing in this subsection may be construed so as to limit the authority of a health care professional who is providing health care services to an individual to request that the individual undergo a genetic test.

(B) Notwithstanding subsection (A), a health insurance issuer may request, but not require, that an individual or a family member of the individual undergo a genetic test if each of the following conditions is met:

(1) the request is made pursuant to research that complies with Part 46 of Title 45, Code of Federal Regulations, or equivalent federal regulations and any applicable state law or regulations for the protection of human subjects in research;

(2) the issuer clearly indicates to each individual, or a person legally authorized to consent on behalf of the individual, to whom the request is made that:

(i) compliance with the request is voluntary; and

(ii) noncompliance will have no effect on enrollment or coverage status or premium or contribution amounts;

(3) no genetic information collected or acquired under this chapter may be used for underwriting purposes;

(4) the issuer notifies the Secretary in writing that the issuer is conducting activities pursuant to the exception provided in this subsection, including a description of the activities conducted; and

(5) the issuer complies with other conditions as the secretary may require by regulation for activities conducted under this subsection.

**SECTION 38‑93‑70.** Health insurance issuer may not request, require, or purchase genetic information for underwriting purposes; exception.

(A)(1) A health insurance issuer may not request, require, or purchase genetic information for underwriting purposes.

(2) An issuer may not request, require, or purchase genetic information with respect to an individual before the individual’s enrollment under the policy or contract of health insurance coverage.

(B) If an issuer obtains genetic information incidental to the requesting, requiring, or purchasing of other information concerning an individual, the request, requirement, or purchase may not be considered a violation of item (2) of subsection (A) if the request, requirement, or purchase is not a violation of item (1) of subsection (A).

**SECTION 38‑93‑80.** Certain actions by health insurance issuers not precluded by chapter.

Nothing in this chapter may be construed so as to preclude a health insurance issuer from:

(1) establishing rules for eligibility for an individual to purchase or enroll for individual coverage based on the manifestation of a disease or disorder in that individual or in a family member of the individual where the family member is covered under the policy or contract of individual health insurance coverage that covers the individual;

(2) adjusting premium or contribution amounts for an individual on the basis of a manifestation of a disease or disorder in that individual or in a family member of the individual where the family member is covered under the policy or contract of health insurance coverage that covers the individual. In this case, the manifestation of a disease or disorder in one individual must not be used as genetic information about other individuals covered under the policy or contract of health insurance coverage issued to the individual and to further increase premiums or contribution amounts;

(3) imposing a preexisting condition exclusion as otherwise permitted by law for an individual with respect to coverage under the policy or contract of health insurance coverage on the basis of a manifestation of a disease or disorder in that individual; or

(4) obtaining and using the results of a genetic test in making a determination regarding payment (as that term is defined for purposes of applying the regulations promulgated by the secretary under Part C of Title XI of the Social Security Act and Section 264 of HIPAA, as may be revised) consistent with the provisions of this chapter. However, the issuer may request only the minimum amount of information necessary to make a determination.

**SECTION 38‑93‑90.** Violations.

(A) A violation of this chapter, including a single instance of a prohibited practice, is an unfair trade practice pursuant to Chapter 57, Title 38 and is subject to the penalties as provided for in Chapter 57 and in Section 38‑2‑10. The director or his designee at any time may examine an issuer, producer, agency, or insurance support organization to enforce this chapter. The expense of examination must be paid by the issuer, producer, agency, or insurance support organization. If an issuer, producer, agency, or insurance support organization determines that the fees assessed are unreasonable in relation to the examination performed, the issuer, producer, agency, or insurance support organization may appeal the assessments to the Administrative Law Court. Examination fees must be retained by the department and are considered “other” funds.

(B) In addition, a violation of this chapter is an unfair trade practice as defined in Section 39‑5‑20 and is subject to the provisions of Sections 39‑5‑110 to 39‑5‑160.

(C) The penalties and enforcement provisions of subsections (A) and (B) are in addition to penalties and enforcement provisions of federal law, including those set forth in the Genetic Information Nondiscrimination Act of 2008, Public Law 110‑233.

(D) An individual who is injured by a person’s violation of this chapter may recover in a court of competent jurisdiction the following remedies:

(1) equitable relief, which may include a retroactive order, directing the person to provide health insurance appropriate to the injured individual under the same terms and conditions as would have applied had the violation not occurred; and

(2) an amount equal to any actual damages suffered by the individual as a result of the violation.

(E) The prevailing party in an action under this section may recover costs and reasonable attorney’s fees.