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S T A T E O F R H O D E I S L A N D

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2025

A N A C T

RELATING TO COMMERCIAL LAW--GENERAL REGULATORY PROVISIONS -- GENETIC INFORMATION PRIVACY ACT

Introduced By: Senators Zurier, Valverde, and Euer

Date Introduced: March 14, 2025

Referred To: Senate Commerce

It is enacted by the General Assembly as follows:

SECTION 1. Legislative findings and short title.

(a) The general assembly finds and declares the following:

(1) Direct-to-consumer genetic testing services are largely unregulated and could expose personal and genetic information, and potentially create unintended security consequences and increased risk.

(2) There is growing concern in the scientific community that outside parties are exploiting the use of genetic data for questionable purposes, including mass surveillance and the ability to track individuals without their authorization.

(3) Genomic data is highly distinguishable. There is a confirmation that a sequence of 30 to 80 single nucleotide polymorphisms could uniquely identify an individual. Genomic data is also very stable. It undergoes little change over the lifetime of an individual and thus has a long-lived value, as opposed to other biometric data such as blood tests, which have expiration dates.

(4) The potential information hidden within genomic data is cause for significant concern. As our knowledge in genomics evolves, so will our view on the sensitivity of genomic data.

(b) Short title. This chapter shall be known, and may be cited, as the "Genetic Information Privacy Act."

SECTION 2. Title 6 of the General Laws entitled "COMMERCIAL LAW — GENERAL REGULATORY PROVISIONS" is hereby amended by adding thereto the following chapter:

CHAPTER 61

GENETIC INFORMATION PRIVACY ACT

6-61-1. Definitions.

For purposes of this chapter, the following definitions apply:

(1) "Affirmative authorization" means an action that demonstrates an intentional decision by the consumer.

(2) "Biological sample" means any material part of the human, discharge therefrom, or derivative thereof, such as tissue, blood, urine, or saliva, known to contain deoxyribonucleic acid (DNA).

(3) "Consumer" means a natural person who is a Rhode Island resident.

(4) "Dark pattern" means a user interface designed or manipulated with the substantial effect of subverting or impairing user autonomy, decision making, or choice.

(5) "Direct-to-consumer genetic testing company" means an entity that does any of the following:

(i) Sells, markets, interprets, or otherwise offers consumer-initiated genetic testing products or services directly to consumers.

(ii) Analyzes genetic data obtained from a consumer, except to the extent that the analysis is performed by a person licensed in the healing arts for diagnosis or treatment of a medical condition.

(iii) Collects, uses, maintains, or discloses genetic data collected or derived from a direct-to-consumer genetic testing product or service, or is directly provided by a consumer.

(6) "Express consent" means a consumer's affirmative authorization to grant permission in response to a clear, meaningful, and prominent notice regarding the collection, use, maintenance, or disclosure of genetic data for a specific purpose. The nature of the data collection, use, maintenance, or disclosure shall be conveyed in clear and prominent terms in such a manner that an ordinary consumer would notice and understand it. Express consent cannot be inferred from inaction. Agreement obtained through use of dark patterns does not constitute consent.

(7)(i) "Genetic data" means any data, regardless of its format, that results from the analysis of a biological sample from a consumer, or from another element enabling equivalent information to be obtained, and concerns genetic material. Genetic material includes, but is not limited to, deoxyribonucleic acids (DNA), ribonucleic acids (RNA), genes, chromosomes, alleles, genomes, alterations or modifications to DNA or RNA, single nucleotide polymorphisms (SNPs), uninterpreted data that results from the analysis of the biological sample, and any information extrapolated, derived, or inferred therefrom.

(ii) "Genetic data" does not include deidentified data. For purposes of this subsection, "deidentified data" means data that cannot be used to infer information about, or otherwise be linked to, a particular individual; provided that, the business that possesses the information does all of the following:

(A) Takes reasonable measures to ensure that the information cannot be associated with a consumer or household;

(B) Publicly commits to maintain and use the information only in deidentified form and not to attempt to reidentify the information, except that the business may attempt to reidentify the information solely for the purpose of determining whether its deidentification processes satisfy the requirements of this subsection; provided that, the business does not use or disclose any information reidentified in this process and destroys the reidentified information upon completion of that assessment; and

(C) Contractually obligates any recipients of the information to take reasonable measures to ensure that the information cannot be associated with a consumer or household and to commit to maintaining and using the information only in deidentified form and not to reidentify the information;

(iii) "Genetic data" does not include data or a biological sample to the extent that data or a biological sample is collected, used, maintained, and disclosed exclusively for scientific research conducted by an investigator with an institution that holds an assurance with the United States Department of Health and Human Services pursuant to Part 46 (commencing with Section 46.101) of Title 45 of the Code of Federal Regulations, in compliance with all applicable federal and state laws and regulations for the protection of human subjects in research including, but not limited to, the Common Rule pursuant to Part 46 (commencing with Section 46.101) of Title 45 of the Code of Federal Regulations, United States Food and Drug Administration regulations pursuant to Parts 50 and 56 of Title 21 of the Code of Federal Regulations, and the federal Family Educational Rights and Privacy Act (20 U.S.C. Sec. 1232g).

(8) "Genetic testing" means any laboratory test of a biological sample from a consumer for the purpose of determining information concerning genetic material contained within the biological sample, or any information extrapolated, derived, or inferred therefrom.

(9) "Person" means an individual, partnership, corporation, association, business, business trust, or legal representative of an organization.

(10) "Service provider" means a sole proprietorship, partnership, limited liability company, corporation, association, or other legal entity that is organized or operated for the profit or financial benefit of its shareholders or other owners, that is involved in the collection, transportation, and

analysis of the consumer's biological sample or extracted genetic material on behalf of the direct-to-consumer genetic testing company, or on behalf of any other company that collects, uses, maintains, or discloses genetic data collected or derived from a direct-to-consumer genetic testing product or service, or is directly provided by a consumer, or the delivery of the results of the analysis of the biological sample or genetic material. The contract between the company and the service provider shall prohibit the service provider from retaining, using, or disclosing the biological sample, extracted genetic material, genetic data, or any information regarding the identity of the consumer, including whether that consumer has solicited or received genetic testing, as applicable, for any purpose other than for the specific purpose of performing the services specified in the contract for the business, including both of the following:

(i) A provision prohibiting the service provider from retaining, using, or disclosing the biological sample, extracted genetic material, genetic data, or any information regarding the identity of the consumer, including whether that consumer has solicited or received genetic testing, as applicable, for a commercial purpose other than providing the services specified in the contract with the business; and

(ii) A provision prohibiting the service provider from associating or combining the biological sample, extracted genetic material, genetic data, or any information regarding the identity of the consumer, including whether that consumer has solicited or received genetic testing, as applicable, with information the service provider has received from or on behalf of another person or persons, or has collected from its own interaction with consumers or as required by law.

6-61-2. Privacy of genetic data.

(a) To safeguard the privacy, confidentiality, security, and integrity of a consumer's genetic data, a direct-to-consumer genetic testing company shall do both of the following:

(1) Provide clear and complete information regarding the company's policies and procedures for the collection, use, maintenance, and disclosure, as applicable, of genetic data by making available to a consumer all of the following:

(i) A summary of its privacy practices, written in plain language, that includes information about the company's collection, use, maintenance, and disclosure, as applicable, of genetic data;

(ii) A prominent and easily accessible privacy notice that includes, at a minimum, complete information about the company's data collection, consent, use, access, disclosure, maintenance, transfer, security, and retention and deletion practices, and information that clearly describes how to file a complaint alleging a violation of this chapter; and

(iii) A notice that the consumer's deidentified genetic or phenotypic information may be shared with or disclosed to third parties for research purposes in accordance with Part 46

(commencing with Section 46.101) of Title 45 of the Code of Federal Regulations.

(2) Obtain a consumer's express consent for collection, use, and disclosure of the consumer's genetic data, including, at a minimum, separate and express consent for each of the following:

(i) The use of the genetic data collected through the genetic testing product or service offered to the consumer, including who has access to genetic data, and how genetic data may be shared, and the specific purposes for which it will be collected, used, and disclosed;

(ii) The storage of a consumer's biological sample after the initial testing requested by the consumer has been fulfilled;

(iii) Each use of genetic data or the biological sample beyond the primary purpose of the genetic testing or service and inherent contextual uses;

(iv) Each transfer or disclosure of the consumer's genetic data or biological sample to a third party other than to a service provider, including the name of the third party to which the consumer's genetic data or biological sample will be transferred or disclosed;

(v)(A) The marketing or facilitation of marketing to a consumer based on the consumer's genetic data or the marketing or facilitation of marketing by a third party based upon the consumer having ordered, purchased, received, or used a genetic testing product or service;

(B) This subsection does not require a direct-to-consumer genetic testing company to obtain a consumer's express consent to market to the consumer on the company's own website or mobile application based upon the consumer having ordered, purchased, received, or used a genetic testing product or service from that company if the content of the advertisement does not depend upon any information specific to that consumer, except for the product or service that the consumer ordered, purchased, received, or used, and the placement of the advertisement is not intended to result in disparate exposure to advertising content. Nothing in this subsection alters, limits, or negates the requirements of any other antidiscrimination law or targeted advertising law;

(C) Any advertisement of a third-party product or service presented to a consumer shall be prominently labeled as advertising content and be accompanied by the name of any third party that has contributed to the placement of the advertising. If applicable, the advertisement also shall clearly indicate that the advertised product or service, and any associated claims, have not been vetted or endorsed by the direct-to-consumer genetic testing company;

(D) For the purpose of this section, "third party" does not include a public or private nonprofit postsecondary educational institution to the extent that the consumer's genetic data or biological sample is disclosed to a public or private nonprofit postsecondary educational institution for the purpose of scientific research or educational activities as described in § 6-61-5. A company

that is subject to the requirements described in this section shall provide effective mechanisms, without any unnecessary steps, for a consumer to revoke their consent after it is given, at least one of which utilizes the primary medium through which the company communicates with consumers.

(b) If a consumer revokes the consent that they provided pursuant to this section, the company shall honor the consumer's consent revocation as soon as practicable, but not later than thirty (30) days after the individual revokes consent, in accordance with both of the following:

(1) Revocation of consent under this section shall comply with Part 46 of Title 45 of the Code of Federal Regulations; and

(2) The company shall destroy a consumer's biological sample within thirty (30) days of receipt of revocation of consent to store the sample.

(c) The direct-to-consumer genetic testing company shall do both of the following:

(1) Implement and maintain reasonable security procedures and practices to protect a consumer's genetic data against unauthorized access, destruction, use, modification, or disclosure; and

(2) Develop procedures and practices to enable a consumer to easily do any of the following;

(i) Access the consumer's genetic data;

(ii) Delete the consumer's account and genetic data, except for genetic data that is required to be retained by the company to comply with applicable legal and regulatory requirements; or

(iii) Have the consumer's biological sample destroyed.

(d) A person or public entity shall not discriminate against a consumer because the consumer exercised any of the consumer's rights under this chapter by doing any of the following including, but not limited to:

(1) Denying goods, services, or benefits to the customer;

(2) Charging different prices or rates for goods or services, including through the use of discounts or other incentives or imposing penalties;

(3) Providing a different level or quality of goods, services, or benefits to the consumer;

(4) Suggesting that the consumer will receive a different price or rate for goods, services, or benefits, or a different level or quality of goods, services, or benefits;

(5) Considering the consumer's exercise of rights under this chapter as a basis for suspicion of criminal wrongdoing or unlawful conduct.

(e)(1) Notwithstanding any other provision in this section, and except as provided in subsection (e)(2) of this section, a direct-to-consumer genetic testing company shall not disclose a consumer's genetic data to any entity that is responsible for administering or making decisions

regarding health insurance, life insurance, long-term care insurance, disability insurance, or employment or to any entity that provides advice to an entity that is responsible for performing those functions;

(2) A direct-to-consumer genetic testing company may disclose a consumer's genetic data or biological sample to an entity described in subsection (e)(1) of this section if all of the following are true:

(i) The entity is not primarily engaged in administering health insurance, life insurance, long-term care insurance, disability insurance, or employment;

(ii) The consumer's genetic data or biological sample is not disclosed to the entity in that entity's capacity as a party that is responsible for administering, advising, or making decisions regarding health insurance, life insurance, long-term care insurance, disability insurance, or employment; and

(iii) Any agent or division of the entity that is involved in administering, advising, or making decisions regarding health insurance, life insurance, long-term care insurance, disability insurance, or employment is prohibited from accessing the consumer's genetic data or biological sample.

6-61-3. Penalties.

(a) Any person who negligently violates this chapter shall be assessed a civil penalty in an amount not to exceed one thousand dollars ($1,000) plus court costs, as determined by the court.

(b) Any person who willfully violates this chapter shall be assessed a civil penalty in an amount not less than one thousand dollars ($1,000) and not more than ten thousand dollars ($10,000) plus court costs, as determined by the court.

(c) Actions for relief pursuant to this chapter shall be prosecuted exclusively in a court of competent jurisdiction by the attorney general.

(d) Court costs recovered pursuant to this section shall be paid to the party or parties that prosecuted the violation. Penalties recovered pursuant to this section shall be paid to the individual to whom the genetic data at issue pertains.

(e) Any provision of a contract or agreement between a consumer and a person governed by this chapter that has, or would have, the effect of delaying or limiting access to a legal remedy for a violation of this chapter shall not apply to the exercise of rights or enforcement pursuant to this chapter.

(f) Each violation of this chapter is a separate and actionable violation.

6-61-4. Conflicts of law.

(a) The provisions of this chapter shall not reduce a direct-to-consumer genetic testing

company's duties, obligations, requirements, or standards under any applicable state and federal laws for the protection of privacy and security.

(b) In the event of a conflict between the provisions of this chapter and any other law, the provisions of the law that afford the greatest protection for the right of privacy for consumers shall control.

6-61-5. Exclusions.

(a) This chapter shall not apply to any of the following:

(1) Medical information governed by chapter 37.3 of title 5, ("confidentiality of medical information act") or to protected health information that is collected, maintained, used, or disclosed by a covered entity or business associate governed by the privacy, security, and breach notification rules issued by the United States Department of Health and Human Services, Parts 160 and 164 of Title 45 of the Code of Federal Regulations established pursuant to the federal Health Insurance Portability and Accountability Act of 1996 (Public Law 104-191) and the federal Health Information Technology for Economic and Clinical Health Act (Public Law 111-5);

(2) A provider of health care governed by chapter 37.3 of title 5, or a covered entity governed by the privacy, security, and breach notification rules issued by the United States Department of Health and Human Services, Parts 160 and 164 of Title 45 of the Code of Federal Regulations, established pursuant to the Health Insurance Portability and Accountability Act of 1996 (Public Law 104-191) and the federal Health Information Technology for Economic and Clinical Health Act, Title XIII of the federal American Recovery and Reinvestment Act of 2009 (Public Law 111-5), to the extent that the provider or covered entity maintains, uses, and discloses genetic information in the same manner as medical information or protected health information, as described in subsection (a)(1) of this section;

(3) A business associate of a covered entity governed by the privacy, security, and data breach notification rules issued by the United States Department of Health and Human Services, Parts 160 and 164 of Title 45 of the Code of Federal Regulations, established pursuant to the federal Health Insurance Portability and Accountability Act of 1996 (Public Law 104-191) and the federal Health Information Technology for Economic and Clinical Health Act, Title XIII of the federal American Recovery and Reinvestment Act of 2009 (Public Law 111-5), to the extent that the business associate maintains, uses, and discloses genetic information in the same manner as medical information or protected health information, as described in subsection (a)(1) of this section;

(4) Scientific research or educational activities conducted by a public or private nonprofit postsecondary educational institution that holds an assurance with the United States Department of Health and Human Services pursuant to Part 46 of Title 45 of the Code of Federal Regulations, to

the extent that the scientific research and educational activities conducted by that institution comply with all applicable federal and state laws and regulations for the protection of human subjects in research including, but not limited to, the Common Rule pursuant to Part 46 (commencing with Section 46.101) of Title 45 of the Code of Federal Regulations, United States Food and Drug Administration regulations pursuant to Parts 50 and 56 of Title 21 of the Code of Federal Regulations, the federal Family Educational Rights and Privacy Act (20 U.S.C. Sec. 1232g);

(5) The provisions of the newborn screening program pursuant to § 23-13-14;

(6) Tests conducted exclusively to diagnose whether an individual has a specific disease, to the extent that all persons involved in the conduct of the test maintain, use, and disclose genetic information in the same manner as medical information or protected health information, as described in subsection (a)(1) of this section; or

(7) Genetic data used or maintained by an employer, or disclosed by an employee to an employer, to the extent that the use, maintenance, or disclosure of that data is necessary to comply with a local, state, or federal workplace health and safety ordinance, law, or regulation.

(b) Nothing in this chapter shall be construed to affect access to information made available to the public by the consumer.

6-61-6. Severability.

The provisions of this chapter are severable. If any provision of this chapter or its application is held invalid, that invalidity shall not affect other provisions or applications that can be given effect without the invalid provision or application.

SECTION 3. This act shall take effect upon passage.

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EXPLANATION

BY THE LEGISLATIVE COUNCIL

OF

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RELATING TO COMMERCIAL LAW--GENERAL REGULATORY PROVISIONS -- GENETIC INFORMATION PRIVACY ACT

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This act would establish the Genetic Information Privacy Act, which would require a direct-to-consumer genetic testing company, as defined, to provide a consumer with certain information regarding the company's policies and procedures for the collection, use, maintenance, and disclosure, as applicable, of genetic data, and to obtain a consumer's express consent for collection, use, or disclosure of the consumer's genetic data, as specified.

This act would take effect upon passage.

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