

119TH CONGRESS
1ST SESSION

S. 863

To provide consumers with the right to delete their genomic data, and for other purposes.

IN THE SENATE OF THE UNITED STATES

MARCH 5, 2025

Mr. CASSIDY (for himself and Mr. PETERS) introduced the following bill; which was read twice and referred to the Committee on Commerce, Science, and Transportation

A BILL

To provide consumers with the right to delete their genomic data, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Genomic Data Protec-
5 tion Act”.

6 **SEC. 2. CONSUMER RIGHTS REGARDING PRIVACY OF**
7 **GENOMIC DATA.**

8 (a) REQUIREMENTS.—

9 (1) CONSUMER CONTROLS.—

1 (A) IN GENERAL.—A direct-to-consumer
2 genomic testing company shall provide a simple
3 and effective mechanism to allow a consumer
4 to—

5 (i) access the genomic data of the con-
6 sumer; and

7 (ii) subject to paragraph (4)—

8 (I) delete the account of the con-
9 sumer, including any genomic data as-
10 sociated with such account; and

11 (II) request the destruction of
12 any biological sample of the consumer.

13 (B) REQUIRED MECHANISM.—The direct-
14 to-consumer genomic testing company shall
15 make available to a consumer the mechanism
16 described in subparagraph (A) through the pri-
17 mary means by which the company commu-
18 nicates with the consumer.

19 (2) NOTIFICATION.—

20 (A) CONSUMER CONTROLS AND USE OF
21 DEIDENTIFIED GENOMIC DATA.—A direct-to-
22 consumer genomic testing company shall make
23 available, in a clear and conspicuous, not mis-
24 leading, and easy-to-read manner a notice
25 that—

1 (i) provides a detailed and accurate
2 representation of the rights set forth in
3 clauses (i) and (ii) of paragraph (1)(A);
4 and

5 (ii) discloses that the deidentified
6 genomic data of a consumer may be shared
7 or disclosed to conduct medical or scientific
8 research, consistent with the privacy regu-
9 lations promulgated under section 264(c)
10 of the Health Insurance Portability and
11 Accountability Act of 1996 (42 U.S.C.
12 1320d–2 note).

13 (B) PURCHASE OF COMPANY.—In the
14 event that a direct-to-consumer genomic testing
15 company is purchased or otherwise acquired by
16 another entity, the direct-to-consumer genomic
17 testing company shall send to each consumer,
18 not fewer than 30 days prior to the date on
19 which the purchase or acquisition is complete, a
20 notice that includes—

21 (i) the identity of the entity pur-
22 chasing or otherwise acquiring the com-
23 pany; and

24 (ii) a detailed and accurate represen-
25 tation of the how a consumer can exercise

1 the rights set forth in clauses (i) and (ii)
2 of paragraph (1)(A) under the new owner-
3 ship.

4 (3) PROCESSING OF DELETION OR DESTRUC-
5 TION REQUESTS.—

6 (A) IN GENERAL.—With respect to a con-
7 sumer's request to delete the genomic data or
8 to destroy the biological sample of the con-
9 sumer, a direct-to-consumer genomic testing
10 company shall—

11 (i) fulfill such request not later than
12 30 days after the date on which the con-
13 sumer makes such request; and

14 (ii) notify the consumer of such dele-
15 tion or destruction not later than 30 days
16 after the deletion or destruction.

17 (B) OUTSTANDING REQUESTS DURING
18 PURCHASE OF COMPANY.—In the event that a
19 direct-to-consumer genomic testing company is
20 purchased or otherwise acquired by another en-
21 tity while a consumer's request to delete the
22 genomic data or to destroy the biological sample
23 of the consumer is outstanding—

24 (i) the entity that is purchasing or
25 otherwise acquiring the company shall

1 comply with the requirements described in
2 subparagraph (A); and

3 (ii) the 30-day period to fulfill such
4 request shall begin on the date on which
5 the consumer makes such request to the
6 direct-to-consumer genomic testing com-
7 pany.

8 (4) EXCEPTIONS.—A direct-to-consumer
9 genomic testing company shall not permit a con-
10 sumer to exercise a right described in paragraph
11 (1)(A)(ii) if the company determines that the exer-
12 cise of the right would require the deletion of infor-
13 mation—

14 (A) subject to a warrant, lawfully executed
15 subpoena, or other court order; or

16 (B) the company is required to retain in
17 order to comply with any other applicable legal
18 or regulatory requirement.

19 (b) ENFORCEMENT.—

20 (1) UNFAIR OR DECEPTIVE ACTS OR PRAC-
21 TICES.—A violation of this section or a regulation
22 promulgated thereunder shall be treated as a viola-
23 tion of a rule defining an unfair or deceptive act or
24 practice under section 18(a)(1)(B) of the Federal
25 Trade Commission Act (15 U.S.C. 57a(a)(1)(B)).

1 (2) POWERS OF THE COMMISSION.—

2 (A) IN GENERAL.—The Commission shall
3 enforce this section in the same manner, by the
4 same means, and with the same jurisdiction,
5 powers, and duties as though all applicable
6 terms and provisions of the Federal Trade
7 Commission Act (15 U.S.C. 41 et seq.) were in-
8 corporated into and made a part of this section.

9 (B) PRIVILEGES AND IMMUNITIES.—Any
10 person who violates this section or a regulation
11 promulgated thereunder shall be subject to the
12 penalties and entitled to the privileges and im-
13 munities provided in the Federal Trade Com-
14 mission Act (15 U.S.C. 41 et seq.).

15 (C) AUTHORITY PRESERVED.—Nothing in
16 this section shall be construed to limit the au-
17 thority of the Commission under any other pro-
18 vision of law.

19 (D) RULEMAKING.—Not later than 1 year
20 after the date of enactment of this section, the
21 Commission may promulgate in accordance with
22 section 553 of title 5, United States Code, such
23 rules as may be necessary to carry out this sec-
24 tion.

25 (c) DEFINITIONS.—In this section:

1 (1) BIOLOGICAL SAMPLE.—The term “biological
2 sample” means any material part of the human, dis-
3 charge therefrom, or derivative thereof, such as tis-
4 sue, blood, urine, or saliva, known to contain
5 deoxyribonucleic acid (DNA).

6 (2) COMMISSION.—The term “Commission”
7 means the Federal Trade Commission.

8 (3) CONSUMER.—The term “consumer” means
9 an individual who provides a biological sample to a
10 direct-to-consumer genomic testing company.

11 (4) DEIDENTIFIED GENOMIC DATA.—The term
12 “deidentified genomic data” means data that cannot
13 be used to infer information about, or otherwise be
14 linked to, a particular individual, provided that the
15 business that possesses the information does all of
16 the following:

17 (A) Takes reasonable measures to ensure
18 that the information cannot be associated with
19 a particular individual.

20 (B) Publicly commits to maintain and use
21 the information only in deidentified form and
22 not to attempt to reidentify the information, ex-
23 cept that the business may attempt to reiden-
24 tify the information solely for the purpose of
25 determining whether its deidentification proc-

esses satisfy the requirements of this subparagraph, 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.

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

(5) DIRECT-TO-CONSUMER GENOMIC TESTING COMPANY.—

(A) IN GENERAL.—The term “direct-to-consumer genomic testing company” means a person that does any of the following:

(i) Manufactures or develops genomic testing products or services for sale directly to consumers.

(ii) Analyzes or interprets genomic data obtained from a consumer.

(iii) Collects, uses, maintains, or discloses genomic data collected or derived

from a direct-to-consumer genomic testing product or service.

(iv) Purchases or acquires genomic data from a direct-to-consumer genomic testing company.

(B) EXCLUSION FOR HEALTH CARE PROFESSIONALS.—The term “direct-to-consumer genomic testing company” shall not include a health care professional (as defined in section 225 of the Public Health Service Act (42 U.S.C. 234)) that performs an action described in subparagraph (A) for purposes of diagnosis or treatment of a medical condition.

(6) GENOMIC DATA.—

(A) IN GENERAL.—The term “genomic data”—

(i) means any data, regardless of its format or whether the data has been deidentified, that results from the analysis of a biological sample from a consumer and concerns genomic material; and

(ii) includes—

(I) deoxyribonucleic acids (DNA), ribonucleic acids (RNA), genes, chromosomes, alleles, genomes, alterations

1 or modifications to DNA or RNA, and
2 single nucleotide polymorphisms
3 (SNPs);

4 (II) uninterpreted data that re-
5 sults from the analysis of the biologi-
6 cal sample; or

7 (III) any information extrapo-
8 lated, derived, or inferred therefrom.

9 (B) EXCLUSION OF DEIDENTIFIED
10 GENOMIC DATA.—The term “genomic data”
11 shall not include the deidentified genomic data
12 of a consumer to the extent that such data is
13 used to conduct medical or scientific research,
14 consistent with the privacy regulations promul-
15 gated under section 264(c) of the Health Insur-
16 ance Portability and Accountability Act of 1996
17 (42 U.S.C. 1320d–2 note).

18 (7) GENOMIC TESTING PRODUCT OR SERV-
19 ICE.—The term “genomic testing product or serv-
20 ice” means any testing product or service that ana-
21 lyzes or interprets the genomic data or biological
22 sample of a consumer.

23 (d) RELATIONSHIP TO FEDERAL AND STATE
24 LAWS.—

1 (1) FEDERAL LAW PRESERVATION.—Nothing in
2 this Act, or a regulation promulgated under this Act,
3 shall be construed to limit any other provision of
4 Federal law, except as specifically provided in this
5 Act.

6 (2) STATE LAW PRESERVATION.—Nothing in
7 this Act, or a regulation promulgated under this Act,
8 shall be construed to preempt, displace, or supplant
9 any State law, except to the extent that a provision
10 of State law conflicts with a provision of this Act,
11 or a regulation promulgated under this Act, and
12 then only to the extent of the conflict.

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