

118TH CONGRESS
2D SESSION

S. _____

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

IN THE SENATE OF THE UNITED STATES

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

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 GENOMIC DATA.**

7 (a) REQUIREMENTS.—

8 (1) CONSUMER CONTROLS.—A direct-to-con-
9 sumer genomic testing company shall develop proce-
10 dures and provide an effective mechanism (including

1 an option that is through the primary medium by
2 which the company communicates with the con-
3 sumer) to allow a consumer to—

4 (A) access the genomic data of the con-
5 sumer; and

6 (B) subject to paragraph (4)—

7 (i) delete the account of the consumer,
8 including any genomic data associated with
9 such account; and

10 (ii) request the destruction of any bio-
11 logical sample of the consumer.

12 (2) NOTIFICATION.—

13 (A) CONSUMER CONTROLS AND USE OF
14 DEIDENTIFIED GENOMIC DATA.—A direct-to-
15 consumer genomic testing company shall make
16 available, in a clear and conspicuous, not mis-
17 leading, and easy-to-read manner a notice
18 that—

19 (i) provides a detailed and accurate
20 representation of the rights set forth in
21 subparagraphs (A) and (B) of paragraph
22 (1); and

23 (ii) discloses that the deidentified
24 genomic data of a consumer may be shared
25 or disclosed to conduct medical or scientific

1 research, consistent with the privacy regu-
2 lations promulgated under section 264(c)
3 of the Health Insurance Portability and
4 Accountability Act of 1996 (42 U.S.C.
5 1320d–2 note).

6 (B) PURCHASE OF COMPANY OR GENOMIC
7 DATA.—In the event that a direct-to-consumer
8 genomic testing company (or the genomic data
9 of such company) is purchased or otherwise ac-
10 quired by another entity, the direct-to-consumer
11 genomic testing company shall send to each
12 consumer, not fewer than 30 days prior to the
13 date on which the purchase or acquisition is
14 complete, a notice that includes—

15 (i) the identity of the entity pur-
16 chasing or otherwise acquiring the com-
17 pany; and

18 (ii) a detailed and accurate represen-
19 tation of the rights set forth in subpara-
20 graphs (A) and (B) of paragraph (1).

21 (3) PROCESSING OF DELETION OR DESTRUC-
22 TION REQUESTS.—With respect to a consumer’s re-
23 quest to delete the genomic data or to destroy the
24 biological sample of the consumer, a direct-to-con-
25 sumer genomic testing company shall—

1 (A) fulfill such request not later than 30
2 days after the date on which the consumer
3 makes such request; and

4 (B) notify the consumer of such deletion or
5 destruction not later than 30 days after the de-
6 letion or destruction.

7 (4) EXCEPTIONS.—A direct-to-consumer
8 genomic testing company shall not permit a con-
9 sumer to exercise a right described in paragraph
10 (1)(B) if the company determines that the exercise
11 of the right would require the deletion of informa-
12 tion—

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

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

18 (b) ENFORCEMENT.—

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

25 (2) POWERS OF THE COMMISSION.—

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

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

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

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

24 (e) 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 that obtains a genomic testing product
10 or service from a direct-to-consumer genomic testing
11 company.

12 (4) DIRECT-TO-CONSUMER GENOMIC TESTING
13 COMPANY.—

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

17 (i) Sells, markets, interprets, analyzes,
18 or otherwise offers genomic testing prod-
19 ucts or services directly to consumers.

20 (ii) Analyzes genomic data obtained
21 from a consumer.

22 (iii) Collects, uses, maintains, or dis-
23 closes genomic data collected or derived
24 from a direct-to-consumer genomic testing
25 product or service.

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

4 (B) EXCLUSION FOR HEALTH CARE PRO-
5 FESSIONALS.—The term “direct-to-consumer
6 genomic testing company” shall not include a
7 health care professional (as defined in section
8 225 of the Public Health Service Act (42
9 U.S.C. 234)) that performs an action described
10 in subparagraph (A) for purposes of diagnosis
11 or treatment of a medical condition.

12 (5) GENOMIC DATA.—

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

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

20 (ii) includes—

21 (I) deoxyribonucleic acids (DNA),
22 ribonucleic acids (RNA), genes, chro-
23 mosomes, alleles, genomes, alterations
24 or modifications to DNA or RNA, and

1 single nucleotide polymorphisms
2 (SNPs);

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

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

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

17 (6) GENOMIC TESTING PRODUCT OR SERV-
18 ICE.—The term “genomic testing product or serv-
19 ice” means any testing product or service that ana-
20 lyzes or otherwise uses the genomic data or biologi-
21 cal sample of a consumer.

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

24 (1) FEDERAL LAW PRESERVATION.—Nothing in
25 this Act, or a regulation promulgated under this Act,

1 shall be construed to limit any other provision of
2 Federal law, except as specifically provided in this
3 Act.

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