

106TH CONGRESS
1ST SESSION

H. R. 293

To amend the Public Health Service Act and the Employee Retirement Income Security Act of 1974 to prohibit health issuers and group health plans from discriminating against individuals on the basis of genetic information.

IN THE HOUSE OF REPRESENTATIVES

JANUARY 6, 1999

Mr. SWEENEY introduced the following bill; which was referred to the Committee on Commerce, and in addition to the Committees on Education and the Workforce, and Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To amend the Public Health Service Act and the Employee Retirement Income Security Act of 1974 to prohibit health issuers and group health plans from discriminating against individuals on the basis of genetic information.

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 “Genetic Information
5 Health Insurance Nondiscrimination Act of 1999”.

1 **SEC. 2. PROHIBITION OF HEALTH INSURANCE DISCRIMINA-**
 2 **TION ON THE BASIS OF GENETIC INFORMA-**
 3 **TION.**

4 (a) GROUP COVERAGE.—

5 (1) AMENDMENTS TO PUBLIC HEALTH SERVICE
 6 ACT.—

7 (A) INCLUSION OF GENETIC TESTING.—

8 Section 2702(a)(1)(F) of the Public Health
 9 Service Act (42 U.S.C. 300gg–1(a)(1)(F)) is
 10 amended by inserting “(or a request for, or re-
 11 ceipt of, genetic information or a genetic test)”
 12 after “genetic information”.

13 (B) LIMITATION ON COLLECTION AND DIS-
 14 CLOSURE OF GENETIC INFORMATION.—Subpart
 15 2 of part A of title XXVII of the Public Health
 16 Service Act is amended by adding at the end
 17 the following new section:

18 **“SEC. 2707. LIMITATION ON COLLECTION AND DISCLOSURE**
 19 **OF GENETIC INFORMATION.**

20 “(a) LIMITATION ON COLLECTION.—A health insur-
 21 ance issuer may not request or require an individual to
 22 whom the issuer provides health insurance coverage in
 23 connection with a group health plan (or an individual who
 24 desires the issuer to provide health insurance coverage in
 25 connection with a group health plan), and a group health
 26 plan may not request or require a participant or bene-

1 ficiary under the plan (or an individual who desires to be-
2 come such a participant or beneficiary), to disclose any
3 genetic information or to obtain any genetic test.

4 “(b) RESTRICTION ON DISCLOSURE.—Subject to sub-
5 section (c), a health insurance issuer in connection with
6 health insurance coverage offered in connection with a
7 group health plan and a group health plan may not dis-
8 close genetic information about an individual (regardless
9 of how the information was obtained) without a prior writ-
10 ten authorization of the individual (or legal representative
11 of the individual) that includes—

12 “(1) a description of the information being dis-
13 closed,

14 “(2) the name of the individual or person to
15 whom the disclosure is being made, and

16 “(3) the purpose of the disclosure.

17 Such authorization is required for each disclosure.

18 “(c) EXCEPTIONS TO DISCLOSURE RESTRICTION.—
19 Genetic information concerning an individual may be dis-
20 closed by a health insurance issuer or group health plan
21 if such disclosure—

22 “(1) is authorized under criminal laws relating
23 to the identification of individuals, or is authorized
24 under Federal or State law and is necessary for the
25 purpose of a criminal or death investigation, a crimi-

1 nal or juvenile proceeding, an inquest, or a child fa-
 2 tality review by a multidisciplinary child abuse team;

3 “(2) is required under the specific order of a
 4 court;

5 “(3) is authorized under law for the purpose of
 6 establishing paternity;

7 “(4) is for the purpose of furnishing genetic in-
 8 formation relating to a decedent to the blood rel-
 9 atives of the decedent for the purpose of medical di-
 10 agnosis; or

11 “(5) is for the purpose of identifying a body.

12 “(d) NOTICE.—A group health plan under this part
 13 shall comply with the notice requirement under section
 14 714(d) of the Employee Retirement Income Security Act
 15 of 1974 with respect to the requirements of this section
 16 as if such section applied to such plan.”.

17 (C) DEFINITIONS.—Section 2791(d) of the
 18 Public Health Service Act (42 U.S.C. 300gg–
 19 91(d)) is amended by adding at the end the fol-
 20 lowing new paragraph:

21 “(15) GENETIC INFORMATION; GENETIC
 22 TEST.—(A) The term ‘genetic information’ means
 23 the information about genes, gene products, or in-
 24 herited characteristics that may derive from an indi-
 25 vidual or a blood-relative of the individual.

1 “(B) The term ‘genetic test’ means a test for
2 determining the presence or absence of genetic char-
3 acteristics in an individual.”.

4 (D) CONFORMING AMENDMENT.—Section
5 2723(c) of such Act (42 U.S.C. 300gg–23(c)) is
6 amended by striking “section 2704” and inserting
7 “sections 2704 and 2707”.

8 (2) ERISA AMENDMENTS.—

9 (A) INCLUSION OF GENETIC TESTING.—
10 Section 702(a)(1)(F) of the Employee Retirement
11 Income Security Act of 1974 (29 U.S.C.
12 1182(a)(1)(F)) is amended by inserting “(or a
13 request for, or receipt of, genetic information or
14 a genetic test)” after “genetic information”.

15 (B) LIMITATION ON COLLECTION AND
16 DISCLOSURE OF GENETIC INFORMATION.—Sub-
17 part B of part 7 of subtitle B of title I of the
18 Employee Retirement Income Security Act of
19 1974 is amended by adding at the end the fol-
20 lowing new section:

21 **“SEC. 714. LIMITATION ON COLLECTION AND DISCLOSURE**
22 **OF GENETIC INFORMATION.**

23 “(a) LIMITATION ON COLLECTION.—A health insur-
24 ance issuer may not request or require an individual to
25 whom the issuer provides health insurance coverage in

1 connection with a group health plan (or an individual who
 2 desires the issuer to provide health insurance coverage in
 3 connection with a group health plan), and a group health
 4 plan may not request or require a participant or bene-
 5 ficiary under the plan (or an individual who desires to be-
 6 come such a participant or beneficiary), to disclose any
 7 genetic information or to obtain any genetic test.

8 “(b) RESTRICTION ON DISCLOSURE.—Subject to sub-
 9 section (c), a health insurance issuer in connection with
 10 health insurance coverage offered in connection with a
 11 group health plan and a group health plan may not dis-
 12 close genetic information about an individual (regardless
 13 of how the information was obtained) without a prior writ-
 14 ten authorization of the individual (or legal representative
 15 of the individual) that includes—

16 “(1) a description of the information being dis-
 17 closed,

18 “(2) the name of the individual or person to
 19 whom the disclosure is being made, and

20 “(3) the purpose of the disclosure.

21 Such authorization is required for each disclosure.

22 “(c) EXCEPTIONS TO DISCLOSURE RESTRICTION.—
 23 Genetic information concerning an individual may be dis-
 24 closed by a health insurance issuer or group health plan
 25 if such disclosure—

1 “(1) is authorized under criminal laws relating
2 to the identification of individuals, or is authorized
3 under Federal or State law and is necessary for the
4 purpose of a criminal or death investigation, a criminal
5 or juvenile proceeding, an inquest, or a child fatality
6 review by a multidisciplinary child abuse team;

7 “(2) is required under the specific order of a
8 court;

9 “(3) is authorized under law for the purpose of
10 establishing paternity;

11 “(4) is for the purpose of furnishing genetic information
12 relating to a decedent to the blood relatives of the decedent
13 for the purpose of medical diagnosis; or
14 agnosis; or

15 “(5) is for the purpose of identifying a body.

16 “(d) NOTICE UNDER GROUP HEALTH PLAN.—The
17 imposition of the requirements of this section shall be
18 treated as a material modification in the terms of the plan
19 described in section 102(a)(1), for purposes of assuring
20 notice of such requirements under the plan; except that
21 the summary description required to be provided under the
22 last sentence of section 104(b)(1) with respect to such
23 modification shall be provided by not later than 60 days
24 after the first day of the first plan year in which such
25 requirements apply.”.

1 (C) DEFINITIONS.—Section 733(d) of the
2 Employee Retirement Income Security Act of
3 1974 (29 U.S.C. 1186(d)) is amended by add-
4 ing at the end the following new paragraph:

5 “(5) GENETIC INFORMATION; GENETIC TEST.—

6 (A) The term ‘genetic information’ means the infor-
7 mation about genes, gene products, or inherited
8 characteristics that may derive from an individual or
9 a blood-relative of the individual.

10 “(B) The term ‘genetic test’ means a test for
11 determining the presence or absence of genetic char-
12 acteristics in an individual.”.

13 “(2) CONSTRUCTION.—Section 731(a)(1) shall
14 not be construed as superseding a State law de-
15 scribed in paragraph (1).”.

16 (D) CONFORMING AMENDMENTS.—(i) Sec-
17 tion 731(c) of such Act (29 U.S.C. 1191(c)) is
18 amended by striking “section 711” and insert-
19 ing “sections 711 and 714”.

20 (ii) Section 732(a) of such Act (29 U.S.C.
21 1191a(a)), as amended by section 603(b)(2) of Pub-
22 lic Law 104–204, is amended by striking “section
23 711” and inserting “sections 711 and 714”.

1 (iii) The table of contents in section 1 of such
 2 Act is amended by inserting after the item relating
 3 to section 713 the following new item:

“Sec. 714. Limitation on collection and disclosure of genetic information.”.

4 (3) INTERNAL REVENUE CODE AMEND-
 5 MENTS.—

6 (A) GENETIC INFORMATION.—Section
 7 9802(a)(1)(F) of the Internal Revenue Code of
 8 1986 is amended by inserting “(or a request
 9 for, or receipt of, genetic information or a ge-
 10 netic test)” after “genetic information”.

11 (B) DEFINITIONS.—Section 9805(d) of
 12 such Act is amended by adding at the end the
 13 following new paragraph:

14 “(6) GENETIC INFORMATION; GENETIC TEST.—

15 (A) The term ‘genetic information’ means the infor-
 16 mation about genes, gene products, or inherited
 17 characteristics that may derive from an individual or
 18 a blood-relative of the individual.

19 “(B) The term ‘genetic test’ means a test for
 20 determining the presence or absence of genetic char-
 21 acteristics in an individual.”.

22 (b) INDIVIDUAL HEALTH INSURANCE.—Part B of
 23 title XXVII of the Public Health Service Act is amended
 24 by inserting after section 2752 the following new section:

1 **“SEC. 2753. LIMITATION ON COLLECTION AND DISCLOSURE**
2 **OF GENETIC INFORMATION.**

3 “(a) IN GENERAL.—The provisions of section 2707
4 (other than subsection (d)) shall apply to health insurance
5 coverage offered by a health insurance issuer in the indi-
6 vidual market in the same manner as it applies to health
7 insurance coverage offered by a health insurance issuer
8 in connection with a group health plan in the small or
9 large group market.

10 “(b) NOTICE.—A health insurance issuer under this
11 part shall comply with the notice requirement under sec-
12 tion 714(d) of the Employee Retirement Income Security
13 Act of 1974 with respect to the requirements referred to
14 in subsection (a) as if such section applied to such issuer
15 and such issuer were a group health plan.”.

16 “(c) EFFECTIVE DATES.—(1) The amendments made
17 by subsection (a) shall apply with respect to group health
18 plans for plan years beginning on or after January 1,
19 2000.

20 “(2) The amendment made by subsection (b) shall
21 apply with respect to health insurance coverage offered,
22 sold, issued, renewed, in effect, or operated in the individ-
23 ual market on or after such date.

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