

105TH CONGRESS
1ST SESSION

H. R. 328

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 7, 1997

Mr. SOLOMON introduced the following bill; which was referred to the Committee on Commerce, and in addition to the Committee on Education and the Workforce, 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 1997”.

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)), as
10 added by section 102(a) of Health Insurance
11 Portability and Accountability Act of 1996, is
12 amended by inserting “(or a request for, or re-
13 ceipt of, genetic information or a genetic test)”
14 after “genetic information”.

15 (B) LIMITATION ON COLLECTION AND DIS-
16 CLOSURE OF GENETIC INFORMATION.—Subpart
17 2 of part A of title XXVII of the Public Health
18 Service Act, as amended by section 703(a) of
19 Public Law 104–204, is amended by adding at
20 the end the following new section:

21 **“SEC. 2706. 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
26 connection with a group health plan (or an individual who

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

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

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

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

19 “(3) the purpose of the disclosure.

20 Such authorization is required for each disclosure.

21 “(c) EXCEPTIONS TO DISCLOSURE RESTRICTION.—
22 Genetic information concerning an individual may be dis-
23 closed by a health insurance issuer or group health plan
24 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 for the purpose of medical
13 diagnosis; or
14

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

16 “(d) NOTICE.—A group health plan under this part
17 shall comply with the notice requirement under section
18 713(d) of the Employee Retirement Income Security Act
19 of 1974 with respect to the requirements of this section
20 as if such section applied to such plan.”.

21 (C) DEFINITIONS.—Section 2791(d) of the
22 Public Health Service Act (42 U.S.C. 300gg–
23 91(d)) is amended by adding at the end the following
24 new paragraph:

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

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

9 (D) CONFORMING AMENDMENT.—Section
10 2723(c) of such Act (42 U.S.C. 300gg–23(c)),
11 as amended by section 604(b)(2) of Public Law
12 104–204, is amended by striking “section
13 2704” and inserting “sections 2704 and 2706”.

14 (2) ERISA AMENDMENTS.—

15 (A) INCLUSION OF GENETIC TESTING.—
16 Section 702(a)(1)(F) of the Employee Retirement
17 Income Security Act of 1974 (29 U.S.C.
18 1182(a)(1)(F)), as added by section 101(a) of
19 Health Insurance Portability and Accountability
20 Act of 1996, is amended by inserting “(or a re-
21 quest for, or receipt of, genetic information or
22 a genetic test)” after “genetic information”.

23 (B) LIMITATION ON COLLECTION AND
24 DISCLOSURE OF GENETIC INFORMATION.—Sub-
25 part B of part 7 of subtitle B of title I of the

1 Employee Retirement Income Security Act of
2 1974, as amended by section 702(a) of Public
3 Law 104–204, is amended by adding at the end
4 the following new section:

5 **“SEC. 713. LIMITATION ON COLLECTION AND DISCLOSURE**
6 **OF GENETIC INFORMATION.**

7 “(a) LIMITATION ON COLLECTION.—A health insur-
8 ance issuer may not request or require an individual to
9 whom the issuer provides health insurance coverage in
10 connection with a group health plan (or an individual who
11 desires the issuer to provide health insurance coverage in
12 connection with a group health plan), and a group health
13 plan may not request or require a participant or bene-
14 ficiary under the plan (or an individual who desires to be-
15 come such a participant or beneficiary), to disclose any
16 genetic information or to obtain any genetic test.

17 “(b) RESTRICTION ON DISCLOSURE.—Subject to sub-
18 section (c), a health insurance issuer in connection with
19 health insurance coverage offered in connection with a
20 group health plan and a group health plan may not dis-
21 close genetic information about an individual (regardless
22 of how the information was obtained) without a prior writ-
23 ten authorization of the individual (or legal representative
24 of the individual) that includes—

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

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

5 “(3) the purpose of the disclosure.

6 Such authorization is required for each disclosure.

7 “(c) EXCEPTIONS TO DISCLOSURE RESTRICTION.—
8 Genetic information concerning an individual may be dis-
9 closed by a health insurance issuer or group health plan
10 if such disclosure—

11 “(1) is authorized under criminal laws relating
12 to the identification of individuals, or is authorized
13 under Federal or State law and is necessary for the
14 purpose of a criminal or death investigation, a crimi-
15 nal or juvenile proceeding, an inquest, or a child fa-
16 tality review by a multidisciplinary child abuse team;

17 “(2) is required under the specific order of a
18 court;

19 “(3) is authorized under law for the purpose of
20 establishing paternity;

21 “(4) is for the purpose of furnishing genetic in-
22 formation relating to a decedent to the blood rel-
23 atives of the decedent for the purpose of medical di-
24 agnosis; or

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

1 “(d) NOTICE UNDER GROUP HEALTH PLAN.—The
2 imposition of the requirements of this section shall be
3 treated as a material modification in the terms of the plan
4 described in section 102(a)(1), for purposes of assuring
5 notice of such requirements under the plan; except that
6 the summary description required to be provided under the
7 last sentence of section 104(b)(1) with respect to such
8 modification shall be provided by not later than 60 days
9 after the first day of the first plan year in which such
10 requirements apply.”.

11 (C) DEFINITIONS.—Section 733(d) of the
12 Employee Retirement Income Security Act of
13 1974 (29 U.S.C. 1186(d)) is amended by add-
14 ing at the end the following new paragraph:

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

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

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

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

1 (D) CONFORMING AMENDMENTS.—(i) Sec-
2 tion 731(e) of such Act (29 U.S.C. 1191(e)), as
3 amended by section 603(b)(1) of Public Law
4 104–204, is amended by striking “section 711”
5 and inserting “sections 711 and 713”.

6 (ii) Section 732(a) of such Act (29 U.S.C.
7 1191a(a)), as amended by section 603(b)(2) of
8 Public Law 104–204, is amended by striking
9 “section 711” and inserting “sections 711 and
10 713”.

11 (iii) The table of contents in section 1 of
12 such Act is amended by inserting after the
13 item relating to section 712 the following new
14 item:

“Sec. 713. Limitation on collection and disclosure of genetic information.”.

15 (3) INTERNAL REVENUE CODE AMEND-
16 MENTS.—

17 (A) GENETIC INFORMATION.—Section
18 9802(a)(1)(F) of the Internal Revenue Code of
19 1986, as added by section 401(a) of the Health
20 Insurance Portability and Accountability Act of
21 1996, is amended by inserting “(or a request
22 for, or receipt of, genetic information or a ge-
23 netic test)” after “genetic information”.

1 (B) DEFINITIONS.—Section 9805(d) of
2 such Act is amended by adding at the end the
3 following new paragraph:

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

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

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

12 (b) INDIVIDUAL HEALTH INSURANCE.—Part B of
13 title XXVII of the Public Health Service Act, as amended
14 by section 605(a) of Public Law 104–204, is amended by
15 inserting after section 2751 the following new section:

16 **“SEC. 2752. LIMITATION ON COLLECTION AND DISCLOSURE**
17 **OF GENETIC INFORMATION.**

18 “(a) IN GENERAL.—The provisions of section 2706
19 (other than subsection (d)) shall apply to health insurance
20 coverage offered by a health insurance issuer in the indi-
21 vidual market in the same manner as it applies to health
22 insurance coverage offered by a health insurance issuer
23 in connection with a group health plan in the small or
24 large group market.

1 “(b) NOTICE.—A health insurance issuer under this
2 part shall comply with the notice requirement under sec-
3 tion 713(d) of the Employee Retirement Income Security
4 Act of 1974 with respect to the requirements referred to
5 in subsection (a) as if such section applied to such issuer
6 and such issuer were a group health plan.”.

7 (c) EFFECTIVE DATES.—(1) The amendments made
8 by subsection (a) shall apply with respect to group health
9 plans for plan years beginning on or after January 1,
10 1998.

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

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