

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.

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## 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

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## 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  
13          for the purpose of medical diagnosis; or  
14          “(5) is for the purpose of identifying a body.

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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