

106TH CONGRESS  
1ST SESSION

# H. R. 306

To prohibit discrimination against individuals and their family members on the basis of genetic information or a request for genetic services.

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## IN THE HOUSE OF REPRESENTATIVES

JANUARY 6, 1999

Ms. SLAUGHTER (for herself, Mr. ABERCROMBIE, Mr. ACKERMAN, Mr. BALDACCI, Mr. BARRETT of Wisconsin, Mr. BENTSEN, Mr. BOUCHER, Mrs. CAPPS, Mr. DEFazio, Mr. DELAHUNT, Ms. DELAURO, Mr. DIXON, Mr. FILNER, Mr. FORD, Mr. FRANK of Massachusetts, Mr. FROST, Mr. GEJDENSON, Mr. GREEN of Texas, Mr. GUTIERREZ, Mr. HINCHEY, Ms. HOOLEY of Oregon, Mr. HORN, Ms. JACKSON-LEE of Texas, Mr. KENNEDY, Mr. KILDEE, Ms. KILPATRICK, Mr. KING, Mr. KLECZKA, Mr. LAFALCE, Mr. LEVIN, Mrs. LOWEY, Mrs. MALONEY of New York, Mr. MASCARA, Ms. MCCARTHY of Missouri, Mr. McNULTY, Mr. MEEHAN, Mr. MEEKS of New York, Ms. MILLENDER-McDONALD, Mr. GEORGE MILLER of California, Mrs. MINK of Hawaii, Mr. MORAN of Virginia, Mrs. MORELLA, Ms. NORTON, Mr. PALLONE, Mr. PRICE of North Carolina, Mr. REGULA, Mr. ROMERO-BARCELO, Ms. ROYBAL-ALLARD, Mr. ROTHMAN, Mr. SANDERS, Mr. SANDLIN, Mr. SCOTT, Mr. SERRANO, Mr. SHERMAN, Mr. SISISKY, Mr. SNYDER, Mr. STARK, Mrs. THURMAN, Mr. WALSH, Ms. WATERS, Mr. WAXMAN, Mr. WISE, Ms. WOOLSEY, Mr. WYNN, and Ms. LEE) introduced the following bill; which was referred to the Committee on Commerce, and in addition to the Committees on Ways and Means, and 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 prohibit discrimination against individuals and their family members on the basis of genetic information or a request for genetic services.

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 Nondiscrimination in Health Insurance Act of 1999”.

6 **SEC. 2. AMENDMENTS TO EMPLOYEE RETIREMENT INCOME**  
7 **SECURITY ACT OF 1974.**

8       (a) IN GENERAL.—Subpart B of part 7 of subtitle  
9 B of title I of the Employee Retirement Income Security  
10 Act of 1974 is amended by adding after section 713 the  
11 following new section:

12 **“SEC. 714. PROHIBITION OF HEALTH INSURANCE DISCRIMI-**  
13 **NATION ON THE BASIS OF GENETIC INFOR-**  
14 **MATION.**

15       “(a) IN GENERAL.—In the case of benefits consisting  
16 of medical care provided under a group health plan or in  
17 the case of health insurance coverage offered by a health  
18 insurance issuer in connection with a group health plan,  
19 the plan or issuer may not deny, cancel, or refuse to renew  
20 such benefits or such coverage, or vary the premiums,  
21 terms, or conditions for such benefits or such coverage,  
22 for any participant or beneficiary under the plan—

23               “(1) on the basis of genetic information; or

24               “(2) on the basis that the participant or bene-  
25 ficiary has requested or received genetic services.

1       “(b) LIMITATION ON COLLECTION AND DISCLOSURE  
2 OF INFORMATION.—

3           “(1) IN GENERAL.—A group health plan, or a  
4 health insurance issuer offering health insurance  
5 coverage in connection with a group health plan,  
6 may not request or require a participant or bene-  
7 ficiary (or an applicant for coverage as a participant  
8 or beneficiary) to disclose to the plan or issuer ge-  
9 netic information about the participant, beneficiary,  
10 or applicant.

11           “(2) REQUIREMENT OF PRIOR AUTHORIZA-  
12 TION.—A group health plan, or a health insurance  
13 issuer offering health insurance coverage in connec-  
14 tion with a group health plan, may not disclose ge-  
15 netic information about a participant or beneficiary  
16 (or an applicant for coverage as a participant or  
17 beneficiary) without the prior written authorization  
18 of the participant, beneficiary, or applicant or of the  
19 legal representative thereof. Such authorization is  
20 required for each disclosure and shall include an  
21 identification of the person to whom the disclosure  
22 would be made.

23       “(c) DEFINITIONS.—For purposes of this section—

24           “(1) GENETIC INFORMATION.—The term ‘ge-  
25 netic information’ means information about genes,

1 gene products, or inherited characteristics that may  
2 derive from an individual or a family member of the  
3 individual.

4 “(2) GENETIC SERVICES.—The term ‘genetic  
5 services’ means health services provided to obtain,  
6 assess, and interpret genetic information for diag-  
7 nostic and therapeutic purposes, and for genetic  
8 education and counselling.

9 “(3) FAMILY MEMBER.—The term ‘family  
10 member’ means, with respect to an individual, an-  
11 other individual related by blood to that individual,  
12 or a spouse or adopted child of the individual.”.

13 (b) DAMAGES.—Section 502(c) of such Act (29  
14 U.S.C. 1132(c)) is amended by adding at the end the fol-  
15 lowing new paragraph:

16 “(7) Any group health plan (as defined in section  
17 733(a)) and any health insurance issuer (as defined in sec-  
18 tion 733(b)(2)) who fails to meet the requirements of sec-  
19 tion 714 with respect to any participant, beneficiary, or  
20 applicant referred to in such section may in the court’s  
21 discretion be liable to such participant, beneficiary, or ap-  
22 plicant for compensatory, consequential, and punitive  
23 damages.”.

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

“Sec. 714. Prohibition of health insurance discrimination on the basis of genetic  
 information.”.

4 (d) EFFECTIVE DATE.—The amendments made by  
 5 this section shall apply with respect to group health plans  
 6 for plan years beginning after 1 year after the date of  
 7 the enactment of this Act.

8 **SEC. 3. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**  
 9 **ACT.**

10 (a) AMENDMENT RELATING TO THE GROUP MAR-  
 11 KET.—

12 (1) IN GENERAL.—Subpart 2 of part A of title  
 13 XXVII of the Public Health Service Act is amended  
 14 by adding after section 2706 the following new sec-  
 15 tion:

16 **“SEC. 2707. PROHIBITION OF HEALTH INSURANCE DIS-**  
 17 **CRIMINATION ON THE BASIS OF GENETIC IN-**  
 18 **FORMATION.**

19 “(a) IN GENERAL.—In the case of benefits consisting  
 20 of medical care provided under a group health plan or in  
 21 the case of health insurance coverage offered by a health  
 22 insurance issuer in connection with a group health plan,  
 23 the plan or issuer may not deny, cancel, or refuse to renew  
 24 such benefits or such coverage, or vary the premiums,

1 terms, or conditions for such benefits or such coverage,  
2 for any participant or beneficiary under the plan—

3 “(1) on the basis of genetic information; or

4 “(2) on the basis that the participant or bene-  
5 ficiary has requested or received genetic services.

6 “(b) LIMITATION ON COLLECTION AND DISCLOSURE  
7 OF INFORMATION.—

8 “(1) IN GENERAL.—A group health plan, or a  
9 health insurance issuer offering health insurance  
10 coverage in connection with a group health plan,  
11 may not request or require a participant or bene-  
12 ficiary (or an applicant for coverage as a participant  
13 or beneficiary) to disclose to the plan or issuer ge-  
14 netic information about the participant, beneficiary,  
15 or applicant.

16 “(2) REQUIREMENT OF PRIOR AUTHORIZA-  
17 TION.—A group health plan, or a health insurance  
18 issuer offering health insurance coverage in connec-  
19 tion with a group health plan, may not disclose ge-  
20 netic information about a participant or beneficiary  
21 (or an applicant for coverage as a participant or  
22 beneficiary) without the prior written authorization  
23 of the participant, beneficiary, or applicant or of the  
24 legal representative thereof. Such authorization is  
25 required for each disclosure and shall include an

1 identification of the person to whom the disclosure  
2 would be made.

3 “(c) DEFINITIONS.—For purposes of this section—

4 “(1) GENETIC INFORMATION.—The term ‘ge-  
5 netic information’ means information about genes,  
6 gene products, or inherited characteristics that may  
7 derive from an individual or a family member of the  
8 individual.

9 “(2) GENETIC SERVICES.—The term ‘genetic  
10 services’ means health services provided to obtain,  
11 assess, and interpret genetic information for diag-  
12 nostic and therapeutic purposes, and for genetic  
13 education and counselling.

14 “(3) FAMILY MEMBER.—The term ‘family  
15 member’ means, with respect to an individual, an-  
16 other individual related by blood to that individual,  
17 or a spouse or adopted child of the individual.”.

18 (2) EFFECTIVE DATE.—The amendment made  
19 by this subsection shall apply with respect to group  
20 health plans for plan years beginning after 1 year  
21 after the date of the enactment of this Act.

22 (b) AMENDMENT RELATING TO THE INDIVIDUAL  
23 MARKET.—

1           (1) IN GENERAL.—Subpart 3 of part B of title  
2           XXVII of such Act is amended by adding after sec-  
3           tion 2752 the following new section:

4           **“SEC. 2753. PROHIBITION OF HEALTH INSURANCE DIS-**  
5                           **CRIMINATION ON THE BASIS OF GENETIC IN-**  
6                           **FORMATION.**

7           “The provisions of section 2707 shall apply to health  
8           insurance coverage offered by a health insurance issuer  
9           in the individual market in the same manner as it applies  
10          to health insurance coverage offered by a health insurance  
11          issuer in connection with a group health plan in the small  
12          or large group market.”.

13          (2) EFFECTIVE DATE.—The amendment made  
14          by this subsection shall apply with respect to health  
15          insurance coverage offered, sold, issued, renewed, in  
16          effect, or operated in the individual market after 1  
17          year after the date of the enactment of this Act.

18          (c) ACTION FOR DAMAGES.—Section 2761 of such  
19          Act (29 U.S.C. 300gg–61) is amended by adding at the  
20          end the following new subsection:

21          “(c) ACTION FOR DAMAGES

22                 “(1) IN GENERAL.—In any case in which a  
23                 group health plan or a health insurance issuer fails  
24                 to meet the applicable requirements of section 2707  
25                 or 2753 with respect to any individual who is a plan

1 participant or beneficiary in such a plan, a covered  
 2 individual, or an applicant for coverage, such indi-  
 3 vidual may bring a civil action under this section. In  
 4 any such action, such plan or issuer may in the  
 5 court's discretion be liable to such individual for  
 6 compensatory, consequential, and punitive damages.

7 “(2) ADDITIONAL PROVISIONS.—For purposes  
 8 of this subsection, the provisions of subsections (d),  
 9 (e), (f), (g), (h), and (j) of section 502 of the Em-  
 10 ployee Retirement Income Security Act of 1974 shall  
 11 apply in connection with such action, the plaintiff in  
 12 such action, and the Secretary of Health and  
 13 Human Services in the same manner and to the  
 14 same extent as such provisions apply in connection  
 15 with actions under such section 502, plaintiffs in  
 16 such actions, and the Secretary of Labor.”.

17 **SEC. 4. AMENDMENTS TO TITLE XVIII OF THE SOCIAL SE-**  
 18 **CURITY ACT RELATING TO MEDIGAP.**

19 (a) IN GENERAL.—Section 1882(s)(2) of the Social  
 20 Security Act (42 U.S.C. 1395ss(s)) is amended by adding  
 21 at the end the following new subparagraph:

22 “(E)(i) An issuer of a medicare supplemental policy  
 23 (as defined in section 1882(g)) may not deny or condition  
 24 the issuance or effectiveness of the policy, and may not

1 discriminate in the pricing of the policy of an eligible  
2 individual—

3 “(I) on the basis of genetic information; or

4 “(II) on the basis that the individual or a fam-  
5 ily member of the individual has requested or re-  
6 ceived genetic services.

7 “(ii) For purposes of this subparagraph—

8 “(I) The term ‘genetic information’ means in-  
9 formation about genes, gene products, or inherited  
10 characteristics that may derive from an individual or  
11 a family member of the individual.

12 “(II) The term ‘genetic services’ means health  
13 services provided to obtain, assess, and interpret ge-  
14 netic information for diagnostic and therapeutic pur-  
15 poses, and for genetic education and counselling.

16 “(III) The term ‘family member’ means, with  
17 respect to an individual, another individual related  
18 by blood to that individual, or a spouse or adopted  
19 child of the individual.”.

20 (b) ACTION FOR DAMAGES.—Section 1882(s) of such  
21 Act is amended further by adding at the end the following  
22 new paragraph:

23 “(4)(A) In any case in which a medicare supple-  
24 mental policy fails to meet the applicable requirements of  
25 paragraph (2)(E) with respect to any individual who is

1 a covered individual or an applicant for coverage, such in-  
2 dividual may bring a civil action under this paragraph. In  
3 any such action, issuer of such policy may in the court's  
4 discretion be liable to such individual for compensatory,  
5 consequential, and punitive damages.

6 “(B) For purposes of this paragraph, the provisions  
7 of subsections (d), (e), (f), (g), (h), and (j) of section 502  
8 of the Employee Retirement Income Security Act of 1974  
9 shall apply in connection with such action, the plaintiff  
10 in such action, and the Secretary of Health and Human  
11 Services in the same manner and to the same extent as  
12 such provisions apply in connection with actions under  
13 such section 502, plaintiffs in such actions, and the Sec-  
14 retary of Labor.”.

15 (c) EFFECTIVE DATE.—The amendments made by  
16 this section shall apply with respect to medicare supple-  
17 mental policies offered, sold, issued, renewed, in effect, or  
18 operated in the individual market after 1 year after the  
19 date of the enactment of this Act.

20 **SEC. 5. AMENDMENTS OF INTERNAL REVENUE CODE OF**  
21 **1986.**

22 (a) IN GENERAL.—Subchapter B of chapter 100 of  
23 the Internal Revenue Code of 1986 (relating to other  
24 group health plan requirements) is amended by adding at  
25 the end the following new section:

1 **“SEC. 9813. PROHIBITION OF DISCRIMINATION BY GROUP**  
2 **HEALTH PLANS ON BASIS OF GENETIC IN-**  
3 **FORMATION.**

4 “(a) **IN GENERAL.**—In the case of benefits consisting  
5 of medical care provided under a group health plan or in  
6 the case of health insurance coverage offered by a health  
7 insurance issuer in connection with a group health plan,  
8 the plan or issuer may not deny, cancel, or refuse to renew  
9 such benefits or such coverage, or vary the premiums,  
10 terms, or conditions for such benefits or such coverage,  
11 for any participant or beneficiary under the plan—

12 “(1) on the basis of genetic information; or

13 “(2) on the basis that the participant or bene-  
14 ficiary has requested or received genetic services.

15 “(b) **LIMITATION ON COLLECTION AND DISCLOSURE**  
16 **OF INFORMATION.**—

17 “(1) **IN GENERAL.**—A group health plan, or a  
18 health insurance issuer offering health insurance  
19 coverage in connection with a group health plan,  
20 may not request or require a participant or bene-  
21 ficiary (or an applicant for coverage as a participant  
22 or beneficiary) to disclose to the plan or issuer ge-  
23 netic information about the participant, beneficiary,  
24 or applicant.

25 “(2) **REQUIREMENT OF PRIOR AUTHORIZA-**  
26 **TION.**—A group health plan, or a health insurance

1 issuer offering health insurance coverage in connec-  
2 tion with a group health plan, may not disclose ge-  
3 netic information about a participant or beneficiary  
4 (or an applicant for coverage as a participant or  
5 beneficiary) without the prior written authorization  
6 of the participant, beneficiary, or applicant or of the  
7 legal representative thereof. Such authorization is  
8 required for each disclosure and shall include an  
9 identification of the person to whom the disclosure  
10 would be made.

11 “(c) DEFINITIONS.—For purposes of this section—

12 “(1) GENETIC INFORMATION.—The term ‘ge-  
13 netic information’ means information about genes,  
14 gene products, or inherited characteristics that may  
15 derive from an individual or a family member of the  
16 individual.

17 “(2) GENETIC SERVICES.—The term ‘genetic  
18 services’ means health services provided to obtain,  
19 assess, and interpret genetic information for diag-  
20 nostic and therapeutic purposes, and for genetic  
21 education and counselling.

22 “(3) FAMILY MEMBER.—The term ‘family  
23 member’ means, with respect to an individual, an-  
24 other individual related by blood to that individual,  
25 or a spouse or adopted child of the individual.”.

1 (b) TECHNICAL AND CONFORMING AMENDMENTS.—

2 (1) Paragraph (1) of section 4980D(f) of such  
3 Code (relating to failure to meet certain group  
4 health plan requirements) is amended by adding at  
5 the end the following new sentence: “For purposes  
6 of applying this section with respect to the require-  
7 ments of section 9813, the term ‘group health plan’  
8 includes an issuer (within the meaning of section  
9 9811).”

10 (2) The table of sections for subchapter B of  
11 chapter 100 of such Code is amended by adding at  
12 the end the following new item:

“Sec. 9813. Prohibition of discrimination by group health plans  
on basis of genetic information.”.

13 (c) EFFECTIVE DATE.—The amendments made by  
14 this section shall apply with respect to group health plans  
15 for plan years beginning after 1 year after the date of  
16 the enactment of this Act.

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