

105TH 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.

IN THE HOUSE OF REPRESENTATIVES

JANUARY 7, 1997

Ms. SLAUGHTER (for herself, Mr. ABERCROMBIE, Mr. ACKERMAN, Mr. BARRETT of Wisconsin, Ms. BROWN of Florida, Mr. BROWN of California, Mrs. CLAYTON, Ms. DANNER, Mr. DEFazio, Mr. DELLUMS, Ms. ESHOO, Mr. EVANS, Mr. GEJDENSON, Mr. GONZALEZ, Mr. GREEN, Mr. HILLIARD, Mr. HINCHEY, Ms. JACKSON-LEE of Texas, Mr. KENNEDY of Massachusetts, Mr. KILDEE, Mr. LAFALCE, Mr. LEWIS of Georgia, Ms. LOFGREN, Mrs. LOWEY, Mrs. MALONEY of New York, Mr. MCDERMOTT, Mrs. MEEK of Florida, Mrs. MORELLA, Mr. NADLER, Mr. PAYNE, Ms. PELOSI, Ms. RIVERS, Mr. SANDERS, Mr. SERRANO, Mr. SMITH of New Jersey, Mr. STARK, Mrs. THURMAN, Mr. TOWNS, Ms. WATERS, Mr. WAXMAN, Ms. DELAURO, Mr. MATSUI, Mr. WATT of North Carolina, and Ms. ROYBAL-ALLARD) 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.

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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Genetic Information
3 Nondiscrimination in Health Insurance Act of 1997”.

4 **SEC. 2. AMENDMENTS TO EMPLOYEE RETIREMENT INCOME**
5 **SECURITY ACT OF 1974.**

6 (a) IN GENERAL.—Subpart B of part 7 of subtitle
7 B of title I of the Employee Retirement Income Security
8 Act of 1974 is amended by inserting after section 712 the
9 following new section:

10 **“SEC. 713. PROHIBITION OF HEALTH INSURANCE DISCRIMI-**
11 **NATION ON THE BASIS OF GENETIC INFOR-**
12 **MATION.**

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

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

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

24 “(b) LIMITATION ON COLLECTION AND DISCLOSURE
25 OF INFORMATION.—

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

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

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

22 “(1) GENETIC INFORMATION.—The term ‘ge-
23 netic information’ means information about genes,
24 gene products, or inherited characteristics that may

1 derive from an individual or a family member of the
2 individual.

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

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

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

15 “(7) Any group health plan (as defined in section
16 733(a)) and any health insurance issuer (as defined in sec-
17 tion 733(b)(2)) who fails to meet the requirements of sec-
18 tion 713 with respect to any participant, beneficiary, or
19 applicant referred to in such section may in the court’s
20 discretion be liable to such participant, beneficiary, or ap-
21 plicant for compensatory, consequential, and punitive
22 damages.”.

23 (c) CLERICAL AMENDMENT.—The table of contents
24 in section 1 of such Act is amended by inserting after the
25 item relating to section 712 the following new item:

“Sec. 713. Prohibition of health insurance discrimination on the basis of genetic information.”.

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

5 **SEC. 3. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**
 6 **ACT.**

7 (a) AMENDMENT RELATING TO THE GROUP MAR-
 8 KET.—

9 (1) IN GENERAL.—Subpart 2 of part A of title
 10 XXVII of the Public Health Service Act is amended
 11 by inserting after section 2705 the following new
 12 section:

13 **“SEC. 2706. PROHIBITION OF HEALTH INSURANCE DIS-**
 14 **CRIMINATION ON THE BASIS OF GENETIC IN-**
 15 **FORMATION.**

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

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

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

3 “(b) LIMITATION ON COLLECTION AND DISCLOSURE
4 OF INFORMATION.—

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

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

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

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

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

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

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

19 (b) AMENDMENT RELATING TO THE INDIVIDUAL
20 MARKET.—

21 (1) IN GENERAL.—Subpart 3 of part B of title
22 XXVII of such Act is amended by inserting after
23 section 2751 the following new section:

1 **“SEC. 2752. PROHIBITION OF HEALTH INSURANCE DIS-**
2 **CRIMINATION ON THE BASIS OF GENETIC IN-**
3 **FORMATION.**

4 “The provisions of section 2705 shall apply to health
5 insurance coverage offered by a health insurance issuer
6 in the individual market in the same manner as it applies
7 to health insurance coverage offered by a health insurance
8 issuer in connection with a group health plan in the small
9 or large group market.”.

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

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

18 “(c) **ACTION FOR DAMAGES**

19 “(1) **IN GENERAL.**—In any case in which a
20 group health plan or a health insurance issuer fails
21 to meet the applicable requirements of section 2706
22 or 2752 with respect to any individual who is a plan
23 participant or beneficiary in such a plan, a covered
24 individual, or an applicant for coverage, such indi-
25 vidual may bring a civil action under this section. In
26 any such action, such plan or issuer may in the

1 court's discretion be liable to such individual for
2 compensatory, consequential, and punitive damages.

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

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

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

18 “(D)(i) An issuer of a medicare supplemental policy
19 (as defined in section 1882(g)) may not deny or condition
20 the issuance or effectiveness of the policy, and may not
21 discriminate in the pricing of the policy of an eligible indi-
22 vidual—

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

1 “(II) on the basis that the individual or a fam-
2 ily member of the individual has requested or re-
3 ceived genetic services.

4 “(ii) For purposes of this subparagraph—

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

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

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

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

20 “(4)(A) In any case in which a medicare supple-
21 mental policy fails to meet the applicable requirements of
22 paragraph (2)(D) respect to any individual who is a cov-
23 ered individual or an applicant for coverage, such individ-
24 ual may bring a civil action under this paragraph. In any

1 such action, issuer of such policy may in the court's discre-
2 tion be liable to such individual for compensatory, con-
3 sequential, and punitive damages.

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

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

18 **SEC. 5. AMENDMENTS OF INTERNAL REVENUE CODE OF**
19 **1986.**

20 (a) IN GENERAL.—Chapter 100 of the Internal Reve-
21 nue Code of 1986 (relating to group health plan port-
22 ability, access, and renewability requirements) is amended
23 by adding at the end the following new subchapter:

1 **“Subchapter B—Prohibition of Discrimina-**
 2 **tion By Group Health Plans on Basis of**
 3 **Genetic Information**

“Sec. 9811. Prohibition of discrimination by group health plans on basis of genetic information.

4 **“SEC. 9811. PROHIBITION OF DISCRIMINATION BY GROUP**
 5 **HEALTH PLANS ON BASIS OF GENETIC IN-**
 6 **FORMATION.**

7 “(a) IN GENERAL.—In the case of benefits consisting
 8 of medical care provided under a group health plan or in
 9 the case of group health insurance coverage offered by a
 10 health insurance issuer in connection with a group health
 11 plan, the plan or issuer may not deny, cancel, or refuse
 12 to renew such benefits or such coverage, or vary the pre-
 13 miums, terms, or conditions for such benefits or such cov-
 14 erage, for any participant or beneficiary under the plan—

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

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

18 “(b) LIMITATION ON COLLECTION AND DISCLOSURE
 19 OF INFORMATION.—

20 “(1) IN GENERAL.—A group health plan, or a
 21 health insurance issuer offering group health insur-
 22 ance coverage in connection with a group health
 23 plan, may not request or require a participant or

1 beneficiary (or an applicant for coverage as a partic-
2 ipant or beneficiary) to disclose to the plan or issuer
3 genetic information about the participant, bene-
4 ficiary, or applicant.

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

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

18 “(1) GENETIC INFORMATION.—The term ‘ge-
19 netic information’ means information about genes,
20 gene products, or inherited characteristics that may
21 derive from an individual or a family member of the
22 individual.

23 “(2) GENETIC SERVICES.—The term ‘genetic
24 services’ means health services provided to obtain,

1 assess, and interpret genetic information for diag-
 2 nostic and therapeutic purposes, and for genetic
 3 education and counselling.

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

8 (b) TECHNICAL AND CONFORMING AMENDMENTS.—

9 (1) Paragraph (1) of section 4980D(f) of such
 10 Code (relating to failure to meet certain group
 11 health plan requirements) is amended by adding at
 12 the end the following new sentence: “For purposes
 13 of applying this section with respect to the require-
 14 ments of subchapter B of chapter 100, the term
 15 ‘group health plan’ includes a health insurance is-
 16 suer (within the meaning of section 9811).”

17 (2) Chapter 100 of such Code is amended by
 18 striking the chapter heading and inserting the fol-
 19 lowing:

20 **“CHAPTER 100—REQUIREMENTS RELAT-**
 21 **ING TO GROUP HEALTH PLANS, ETC.**

“Subchapter A. Group health plan portability, access, and renew-
 ability requirements.

“Subchapter B. Prohibition of discrimination by group health
 plans on basis of genetic information.

1 **“Subchapter A—Group Health Plan Port-**
2 **ability, Access, and Renewability Re-**
3 **quirements”.**

4 (3) The table of chapters for such Code is
5 amended by striking the item relating to chapter
6 100 and inserting the following new item:

Chapter 100. Requirements relating to group health plans, etc.”

7 (4) Subsection (a) of section 4980D of such
8 Code is amended by striking “(relating to group
9 health plan portability, access, and renewability re-
10 quirements)” and inserting “(relating to group
11 health plans, etc., requirements)”.

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

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