

105TH CONGRESS  
1ST SESSION

# S. 89

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 SENATE OF THE UNITED STATES

JANUARY 21, 1997

Ms. SNOWE introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

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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 1997”.

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

1 Act of 1974 is amended by inserting after section 712 the  
 2 following:

3 **“SEC. 713. PROHIBITION OF HEALTH INSURANCE DISCRIMI-**  
 4 **NATION ON THE BASIS OF GENETIC INFOR-**  
 5 **MATION.**

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

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

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

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

19 “(1) IN GENERAL.—A group health plan, or a  
 20 health insurance issuer offering group health insur-  
 21 ance coverage in connection with a group health  
 22 plan, may not request or require a participant or  
 23 beneficiary (or an applicant for coverage as a partic-  
 24 ipant or beneficiary) to disclose to the plan or issuer

1 genetic information about the participant, bene-  
 2 ficiary, or applicant.

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

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

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

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

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

5       (b) DAMAGES.—Section 502(c) of such Act (29  
6 U.S.C. 1132(c)) is amended by adding at the end the fol-  
7       lowing:

8       “(7) Any group health plan (as defined in section  
9       733(a)) and any health insurance issuer (as defined in sec-  
10      tion 733(b)(2)) who fails to meet the requirements of sec-  
11      tion 713 with respect to any participant, beneficiary, or  
12      applicant referred to in such section may in the court’s  
13      discretion be liable to such participant, beneficiary, or ap-  
14      plicant for compensatory, consequential, and punitive  
15      damages.”.

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

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

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

1 **SEC. 3. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**  
 2 **ACT.**

3 (a) AMENDMENT RELATING TO THE GROUP MAR-  
 4 KET.—

5 (1) IN GENERAL.—Subpart 2 of part A of title  
 6 XXVII of the Public Health Service Act is amended  
 7 by inserting after section 2705 the following:

8 **“SEC. 2706. PROHIBITION OF HEALTH INSURANCE DIS-**  
 9 **CRIMINATION ON THE BASIS OF GENETIC IN-**  
 10 **FORMATION.**

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

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

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

22 “(b) LIMITATION ON COLLECTION AND DISCLOSURE  
 23 OF INFORMATION.—

24 “(1) IN GENERAL.—A group health plan, or a  
 25 health insurance issuer offering group health insur-  
 26 ance coverage in connection with a group health

1 plan, may not request or require a participant or  
 2 beneficiary (or an applicant for coverage as a partic-  
 3 ipant or beneficiary) to disclose to the plan or issuer  
 4 genetic information about the participant, bene-  
 5 ficiary, or applicant.

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

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

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

24 “(2) GENETIC SERVICES.—The term ‘genetic  
 25 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            (2) EFFECTIVE DATE.—The amendment made  
 9        by this subsection shall apply with respect to group  
 10       health plans for plan years beginning after 1 year  
 11       after the date of the enactment of this Act.

12        (b) AMENDMENT RELATING TO THE INDIVIDUAL  
 13       MARKET.—

14            (1) IN GENERAL.—Subpart 3 of part B of title  
 15       XXVII of such Act is amended by inserting after  
 16       section 2751 the following:

17        **“SEC. 2752. PROHIBITION OF HEALTH INSURANCE DIS-**  
 18                                **CRIMINATION ON THE BASIS OF GENETIC IN-**  
 19                                **FORMATION.**

20            “The provisions of section 2705 shall apply to health  
 21       insurance coverage offered by a health insurance issuer  
 22       in the individual market in the same manner as it applies  
 23       to health insurance coverage offered by a health insurance  
 24       issuer in connection with a group health plan in the small  
 25       or large group market.”.

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

6           (c) ACTION FOR DAMAGES.—Section 2761 of such  
 7           Act (29 U.S.C. 300gg–61) is amended by adding at the  
 8           end the following:

9           “(c) ACTION FOR DAMAGES

10           “(1) IN GENERAL.—In any case in which a  
 11           group health plan or a health insurance issuer fails  
 12           to meet the applicable requirements of section 2706  
 13           or 2752 with respect to any individual who is a plan  
 14           participant or beneficiary in such a plan, a covered  
 15           individual, or an applicant for coverage, such indi-  
 16           vidual may bring a civil action under this section. In  
 17           any such action, such plan or issuer may in the  
 18           court’s discretion be liable to such individual for  
 19           compensatory, consequential, and punitive damages.

20           “(2) ADDITIONAL PROVISIONS.—For purposes  
 21           of this subsection, the provisions of subsections (d),  
 22           (e), (f), (g), (h), and (j) of section 502 of the Em-  
 23           ployee Retirement Income Security Act of 1974 shall  
 24           apply in connection with such action, the plaintiff in  
 25           such action, and the Secretary of Health and



1 Human Services in the same manner and to the  
 2 same extent as such provisions apply in connection  
 3 with actions under such section 502, plaintiffs in  
 4 such actions, and the Secretary of Labor.”.

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

7 (a) IN GENERAL.—Section 1882(s)(2) of the Social  
 8 Security Act (42 U.S.C. 1395ss(s)) is amended by adding  
 9 at the end the following:

10 “(D)(i) An issuer of a medicare supplemental policy  
 11 (as defined in section 1882(g)) may not deny or condition  
 12 the issuance or effectiveness of the policy, and may not  
 13 discriminate in the pricing of the policy of an eligible indi-  
 14 vidual—

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

16 “(II) on the basis that the individual or a fam-  
 17 ily member of the individual has requested or re-  
 18 ceived genetic services.

19 “(ii) For purposes of this subparagraph—

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

1           “(II) The term ‘genetic services’ means health  
 2           services provided to obtain, assess, and interpret ge-  
 3           netic information for diagnostic and therapeutic pur-  
 4           poses, and for genetic education and counselling.

5           “(III) The term ‘family member’ means, with  
 6           respect to an individual, another individual related  
 7           by blood to that individual, or a spouse or adopted  
 8           child of the individual.”.

9           (b) ACTION FOR DAMAGES.—Section 1882(s) of the  
 10          Social Security Act (42 U.S.C. 1395ss(s)) is amended fur-  
 11          ther by adding at the end the following:

12          “(4)(A) In any case in which a medicare supple-  
 13          mental policy fails to meet the applicable requirements of  
 14          paragraph (2)(D) with respect to any individual who is  
 15          a covered individual or an applicant for coverage, such in-  
 16          dividual may bring a civil action under this paragraph. In  
 17          any such action, the issuer of such policy may in the  
 18          court’s discretion be liable to such individual for compen-  
 19          satory, consequential, and punitive damages.

20          “(B) For purposes of this paragraph, the provisions  
 21          of subsections (d), (e), (f), (g), (h), and (j) of section 502  
 22          of the Employee Retirement Income Security Act of 1974  
 23          shall apply in connection with such action, the plaintiff  
 24          in such action, and the Secretary of Health and Human  
 25          Services in the same manner and to the same extent as

1 such provisions apply in connection with actions under  
 2 such section 502, plaintiffs in such actions, and the Sec-  
 3 retary of Labor.”.

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

9 **SEC. 5. AMENDMENTS OF INTERNAL REVENUE CODE OF**  
 10 **1986.**

11 (a) IN GENERAL.—Chapter 100 of the Internal Reve-  
 12 nue Code of 1986 (relating to group health plan port-  
 13 ability, access, and renewability requirements) is amended  
 14 by adding at the end the following:

15 **“Subchapter B—Prohibition of Discrimina-**  
 16 **tion By Group Health Plans on Basis of**  
 17 **Genetic Information**

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

18 **“SEC. 9811. PROHIBITION OF DISCRIMINATION BY GROUP**  
 19 **HEALTH PLANS ON BASIS OF GENETIC IN-**  
 20 **FORMATION.**

21 “(a) IN GENERAL.—In the case of benefits consisting  
 22 of medical care provided under a group health plan or in  
 23 the case of group health insurance coverage offered by a  
 24 health insurance issuer in connection with a group health

1 plan, the plan or issuer may not deny, cancel, or refuse  
 2 to renew such benefits or such coverage, or vary the pre-  
 3 miums, terms, or conditions for such benefits or such cov-  
 4 erage, for any participant or beneficiary under the plan—

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

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

8 “(b) LIMITATION ON COLLECTION AND DISCLOSURE  
 9 OF INFORMATION.—

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

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

1 legal representative thereof. Such authorization is  
 2 required for each disclosure and shall include an  
 3 identification of the person to whom the disclosure  
 4 would be made.

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

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

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

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

20 (b) TECHNICAL AND CONFORMING AMENDMENTS.—

21 (1) Paragraph (1) of section 4980D(f) of such  
 22 Code (relating to failure to meet certain group  
 23 health plan requirements) is amended by adding at  
 24 the end the following new sentence: “For purposes

1 of applying this section with respect to the require-  
 2 ments of subchapter B of chapter 100, the term  
 3 ‘group health plan’ includes a health insurance is-  
 4 suer (within the meaning of section 9811).”

5 (2) Chapter 100 of such Code is amended by  
 6 striking the chapter heading and inserting the fol-  
 7 lowing:

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

“SUBCHAPTER A. Group health plan portability, access, and re-  
 newability requirements.

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

10 **“Subchapter A—Group Health Plan Port-**  
 11 **ability, Access, and Renewability Re-**  
 12 **quirements”.**

13 (3) The table of chapters for such Code is  
 14 amended by striking the item relating to chapter  
 15 100 and inserting the following:

“CHAPTER 100. Requirements relating to group health plans,  
 etc.”

16 (4) Subsection (a) of section 4980D of such  
 17 Code is amended by striking “(relating to group  
 18 health plan portability, access, and renewability re-  
 19 quirements)” and inserting “(relating to group  
 20 health plans, etc., requirements)”.

21 (c) EFFECTIVE DATE.—The amendments made by  
 22 this section shall apply with respect to group health plans

- 1 for plan years beginning after 1 year after the date of
- 2 the enactment of this Act.

