

107TH CONGRESS
1ST SESSION

S. 382

To prohibit discrimination on the basis of genetic information with respect to health insurance.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 15, 2001

Ms. SNOWE (for herself, Mr. FRIST, Mr. JEFFORDS, Ms. COLLINS, Mr. DEWINE, and Mr. ENZI) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To prohibit discrimination on the basis of genetic information with respect to health insurance.

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 2001”.

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

3 (a) PROHIBITION OF HEALTH DISCRIMINATION ON
 4 THE BASIS OF GENETIC INFORMATION OR GENETIC
 5 SERVICES.—

6 (1) NO ENROLLMENT RESTRICTION FOR GE-
 7 NETIC SERVICES.—Section 702(a)(1)(F) of the Em-
 8 ployee Retirement Income Security Act of 1974 (29
 9 U.S.C. 1182(a)(1)(F)) is amended by inserting be-
 10 fore the period the following: “(including informa-
 11 tion about a request for or receipt of genetic serv-
 12 ices)”.

13 (2) NO DISCRIMINATION IN GROUP PREMIUMS
 14 BASED ON PREDICTIVE GENETIC INFORMATION.—
 15 Subpart B of part 7 of subtitle B of title I of the
 16 Employee Retirement Income Security Act of 1974
 17 (29 U.S.C. 1185 et seq.) is amended by adding at
 18 the end the following:

19 **“SEC. 714. PROHIBITING PREMIUM DISCRIMINATION**
 20 **AGAINST GROUPS ON THE BASIS OF PRE-**
 21 **DICTIVE GENETIC INFORMATION.**

22 “A group health plan, or a health insurance issuer
 23 offering group health insurance coverage in connection
 24 with a group health plan, shall not adjust premium or con-
 25 tribution amounts for a group on the basis of predictive
 26 genetic information concerning an individual in the group

1 or a family member of the individual (including informa-
2 tion about a request for or receipt of genetic services).”.

3 (3) CONFORMING AMENDMENTS.—

4 (A) IN GENERAL.—Section 702(b) of the
5 Employee Retirement Income Security Act of
6 1974 (29 U.S.C. 1182(b)) is amended by add-
7 ing at the end the following:

8 “(3) REFERENCE TO RELATED PROVISION.—

9 For a provision prohibiting the adjustment of pre-
10 mium or contribution amounts for a group under a
11 group health plan on the basis of predictive genetic
12 information (including information about a request
13 for or receipt of genetic services), see section 714.”.

14 (B) TABLE OF CONTENTS.—The table of
15 contents in section 1 of the Employee Retire-
16 ment Income Security Act of 1974 is amended
17 by inserting after the item relating to section
18 713 the following new item:

“Sec. 714. Prohibiting premium discrimination against groups on the basis of
predictive genetic information.”.

19 (b) LIMITATION ON COLLECTION OF PREDICTIVE
20 GENETIC INFORMATION.—Section 702 of the Employee
21 Retirement Income Security Act of 1974 (29 U.S.C. 1182)
22 is amended by adding at the end the following:

23 “(c) COLLECTION OF PREDICTIVE GENETIC INFOR-
24 MATION.—

1 “(1) LIMITATION ON REQUESTING OR REQUIR-
2 ING PREDICTIVE GENETIC INFORMATION.—Except
3 as provided in paragraph (2), a group health plan,
4 or a health insurance issuer offering health insur-
5 ance coverage in connection with a group health
6 plan, shall not request or require predictive genetic
7 information concerning an individual or a family
8 member of the individual (including information
9 about a request for or receipt of genetic services).

10 “(2) INFORMATION NEEDED FOR DIAGNOSIS,
11 TREATMENT, OR PAYMENT.—

12 “(A) IN GENERAL.—Notwithstanding para-
13 graph (1), a group health plan, or a health in-
14 surance issuer offering health insurance cov-
15 erage in connection with a group health plan,
16 that provides health care items and services to
17 an individual or dependent may request (but
18 may not require) that such individual or de-
19 pendent disclose, or authorize the collection or
20 disclosure of, predictive genetic information for
21 purposes of diagnosis, treatment, or payment
22 relating to the provision of health care items
23 and services to such individual or dependent.

24 “(B) NOTICE OF CONFIDENTIALITY PRAC-
25 TICES AND DESCRIPTION OF SAFEGUARDS.—As

1 a part of a request under subparagraph (A),
2 the group health plan, or a health insurance
3 issuer offering health insurance coverage in
4 connection with a group health plan, shall pro-
5 vide to the individual or dependent a descrip-
6 tion of the procedures in place to safeguard the
7 confidentiality, as described in subsection (d),
8 of such predictive genetic information.

9 “(d) CONFIDENTIALITY WITH RESPECT TO PRE-
10 DICTIVE GENETIC INFORMATION.—

11 “(1) NOTICE OF CONFIDENTIALITY PRAC-
12 TICES.—A group health plan, or a health insurance
13 issuer offering health insurance coverage in connec-
14 tion with a group health plan, shall post or provide,
15 in writing and in a clear and conspicuous manner,
16 notice of the plan or issuer’s confidentiality prac-
17 tices, that shall include—

18 “(A) a description of an individual’s rights
19 with respect to predictive genetic information;

20 “(B) the procedures established by the
21 plan or issuer for the exercise of the individ-
22 ual’s rights; and

23 “(C) the right to obtain a copy of the no-
24 tice of the confidentiality practices required
25 under this subsection.

1 “(2) ESTABLISHMENT OF SAFEGUARDS.—A
2 group health plan, or a health insurance issuer offer-
3 ing health insurance coverage in connection with a
4 group health plan, shall establish and maintain ap-
5 propriate administrative, technical, and physical
6 safeguards to protect the confidentiality, security,
7 accuracy, and integrity of predictive genetic informa-
8 tion created, received, obtained, maintained, used,
9 transmitted, or disposed of by such plan or issuer.

10 “(3) COMPLIANCE WITH CERTAIN STAND-
11 ARDS.—With respect to the establishment and main-
12 tenance of safeguards under this subsection or sub-
13 section (c)(2)(B), a group health plan, or a health
14 insurance issuer offering health insurance coverage
15 in connection with a group health plan, shall be
16 deemed to be in compliance with such subsections if
17 such plan or issuer is in compliance with the stand-
18 ards promulgated by the Secretary of Health and
19 Human Services under—

20 “(A) part C of title XI of the Social Secu-
21 rity Act (42 U.S.C. 1320d et seq.); or

22 “(B) section 264(c) of Health Insurance
23 Portability and Accountability Act of 1996
24 (Public Law 104–191; 110 Stat. 2033).”.

1 (c) DEFINITIONS.—Section 733(d) of the Employee
2 Retirement Income Security Act of 1974 (29 U.S.C.
3 1191b(d)) is amended by adding at the end the following:

4 “(5) FAMILY MEMBER.—The term ‘family
5 member’ means with respect to an individual—

6 “(A) the spouse of the individual;

7 “(B) a dependent child of the individual,
8 including a child who is born to or placed for
9 adoption with the individual; and

10 “(C) all other individuals related by blood
11 to the individual or the spouse or child de-
12 scribed in subparagraph (A) or (B).

13 “(6) GENETIC INFORMATION.—The term ‘ge-
14 netic information’ means information about genes,
15 gene products, or inherited characteristics that may
16 derive from an individual or a family member (in-
17 cluding information about a request for or receipt of
18 genetic services).

19 “(7) GENETIC SERVICES.—The term ‘genetic
20 services’ means health services provided to obtain,
21 assess, or interpret genetic information for diag-
22 nostic and therapeutic purposes, and for genetic
23 education and counseling.

24 “(8) PREDICTIVE GENETIC INFORMATION.—

1 “(A) IN GENERAL.—The term ‘predictive
2 genetic information’ means, in the absence of
3 symptoms, clinical signs, or a diagnosis of the
4 condition related to such information—

5 “(i) information about an individual’s
6 genetic tests;

7 “(ii) information about genetic tests
8 of family members of the individual; or

9 “(iii) information about the occur-
10 rence of a disease or disorder in family
11 members.

12 “(B) EXCEPTIONS.—The term ‘predictive
13 genetic information’ shall not include—

14 “(i) information about the sex or age
15 of the individual;

16 “(ii) information derived from phys-
17 ical tests, such as the chemical, blood, or
18 urine analyses of the individual including
19 cholesterol tests; and

20 “(iii) information about physical
21 exams of the individual.

22 “(9) GENETIC TEST.—The term ‘genetic test’
23 means the analysis of human DNA, RNA, chro-
24 mosomes, proteins, and certain metabolites, includ-
25 ing analysis of genotypes, mutations, phenotypes, or

1 karyotypes, for the purpose of predicting risk of dis-
 2 ease in asymptomatic or undiagnosed individuals.
 3 Such term does not include physical tests, such as
 4 the chemical, blood, or urine analyses of the indi-
 5 vidual including cholesterol tests, and physical exams
 6 of the individual, in order to detect symptoms, clin-
 7 ical signs, or a diagnosis of disease.”.

8 (d) **EFFECTIVE DATE.**—Except as provided in this
 9 section, this section and the amendments made by this
 10 section shall apply with respect to group health plans for
 11 plan years beginning 1 year after the date of the enact-
 12 ment of this Act.

13 **SEC. 3. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**
 14 **ACT.**

15 (a) **AMENDMENTS RELATING TO THE GROUP MAR-**
 16 **KET.**—

17 (1) **PROHIBITION OF HEALTH DISCRIMINATION**
 18 **ON THE BASIS OF GENETIC INFORMATION IN THE**
 19 **GROUP MARKET.**—

20 (A) **NO ENROLLMENT RESTRICTION FOR**
 21 **GENETIC SERVICES.**—Section 2702(a)(1)(F) of
 22 the Public Health Service Act (42 U.S.C.
 23 300gg–1(a)(1)(F)) is amended by inserting be-
 24 fore the period the following: “(including infor-

1 mation about a request for or receipt of genetic
2 services)”.

3 (B) NO DISCRIMINATION IN PREMIUMS
4 BASED ON PREDICTIVE GENETIC INFORMA-
5 TION.—Subpart 2 of part A of title XXVII of
6 the Public Health Service Act (42 U.S.C.
7 300gg–4 et seq.) is amended by adding at the
8 end the following new section:

9 **“SEC. 2707. PROHIBITING PREMIUM DISCRIMINATION**
10 **AGAINST GROUPS ON THE BASIS OF PRE-**
11 **DICTIVE GENETIC INFORMATION IN THE**
12 **GROUP MARKET.**

13 “A group health plan, or a health insurance issuer
14 offering group health insurance coverage in connection
15 with a group health plan shall not adjust premium or con-
16 tribution amounts for a group on the basis of predictive
17 genetic information concerning an individual in the group
18 or a family member of the individual (including informa-
19 tion about a request for or receipt of genetic services).”.

20 (C) CONFORMING AMENDMENT.—Section
21 2702(b) of the Public Health Service Act (42
22 U.S.C. 300gg–1(b)) is amended by adding at
23 the end the following:

24 “(3) REFERENCE TO RELATED PROVISION.—
25 For a provision prohibiting the adjustment of pre-

1 mium or contribution amounts for a group under a
 2 group health plan on the basis of predictive genetic
 3 information (including information about a request
 4 for or receipt of genetic services), see section 2707.”.

5 (D) LIMITATION ON COLLECTION AND DIS-

6 CLOSURE OF PREDICTIVE GENETIC INFORMA-

7 TION.—Section 2702 of the Public Health Serv-

8 ice Act (42 U.S.C. 300gg-1) is amended by

9 adding at the end the following:

10 “(c) COLLECTION OF PREDICTIVE GENETIC INFOR-

11 MATION.—

12 “(1) LIMITATION ON REQUESTING OR REQUIR-

13 ING PREDICTIVE GENETIC INFORMATION.—Except

14 as provided in paragraph (2), a group health plan,

15 or a health insurance issuer offering health insur-

16 ance coverage in connection with a group health

17 plan, shall not request or require predictive genetic

18 information concerning an individual or a family

19 member of the individual (including information

20 about a request for or receipt of genetic services).

21 “(2) INFORMATION NEEDED FOR DIAGNOSIS,

22 TREATMENT, OR PAYMENT.—

23 “(A) IN GENERAL.—Notwithstanding para-

24 graph (1), a group health plan, or a health in-

25 surance issuer offering health insurance cov-

1 erage in connection with a group health plan,
2 that provides health care items and services to
3 an individual or dependent may request (but
4 may not require) that such individual or de-
5 pendent disclose, or authorize the collection or
6 disclosure of, predictive genetic information for
7 purposes of diagnosis, treatment, or payment
8 relating to the provision of health care items
9 and services to such individual or dependent.

10 “(B) NOTICE OF CONFIDENTIALITY PRAC-
11 TICES AND DESCRIPTION OF SAFEGUARDS.—As
12 a part of a request under subparagraph (A),
13 the group health plan, or a health insurance
14 issuer offering health insurance coverage in
15 connection with a group health plan, shall pro-
16 vide to the individual or dependent a descrip-
17 tion of the procedures in place to safeguard the
18 confidentiality, as described in subsection (d),
19 of such predictive genetic information.

20 “(d) CONFIDENTIALITY WITH RESPECT TO PRE-
21 DICTIVE GENETIC INFORMATION.—

22 “(1) NOTICE OF CONFIDENTIALITY PRAC-
23 TICES.—A group health plan, or a health insurance
24 issuer offering health insurance coverage in connec-
25 tion with a group health plan, shall post or provide,

1 in writing and in a clear and conspicuous manner,
2 notice of the plan or issuer’s confidentiality prac-
3 tices, that shall include—

4 “(A) a description of an individual’s rights
5 with respect to predictive genetic information;

6 “(B) the procedures established by the
7 plan or issuer for the exercise of the individ-
8 ual’s rights; and

9 “(C) the right to obtain a copy of the no-
10 tice of the confidentiality practices required
11 under this subsection.

12 “(2) ESTABLISHMENT OF SAFEGUARDS.—A
13 group health plan, or a health insurance issuer offer-
14 ing health insurance coverage in connection with a
15 group health plan, shall establish and maintain ap-
16 propriate administrative, technical, and physical
17 safeguards to protect the confidentiality, security,
18 accuracy, and integrity of predictive genetic informa-
19 tion created, received, obtained, maintained, used,
20 transmitted, or disposed of by such plan or issuer.

21 “(3) COMPLIANCE WITH CERTAIN STAND-
22 ARDS.—With respect to the establishment and main-
23 tenance of safeguards under this subsection or sub-
24 section (c)(2)(B), a group health plan, or a health
25 insurance issuer offering health insurance coverage

1 in connection with a group health plan, shall be
2 deemed to be in compliance with such subsections if
3 such plan or issuer is in compliance with the stand-
4 ards promulgated by the Secretary of Health and
5 Human Services under—

6 “(A) part C of title XI of the Social Secu-
7 rity Act (42 U.S.C. 1320d et seq.); or

8 “(B) section 264(c) of Health Insurance
9 Portability and Accountability Act of 1996
10 (Public Law 104–191; 110 Stat. 2033).”.

11 (2) DEFINITIONS.—Section 2791(d) of the Pub-
12 lic Health Service Act (42 U.S.C. 300gg–91(d)) is
13 amended by adding at the end the following:

14 “(15) FAMILY MEMBER.—The term ‘family
15 member’ means, with respect to an individual—

16 “(A) the spouse of the individual;

17 “(B) a dependent child of the individual,
18 including a child who is born to or placed for
19 adoption with the individual; and

20 “(C) all other individuals related by blood
21 to the individual or the spouse or child de-
22 scribed in subparagraph (A) or (B).

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

1 derive from an individual or a family member (in-
2 cluding information about a request for or receipt of
3 genetic services).

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

9 “(18) PREDICTIVE GENETIC INFORMATION.—

10 “(A) IN GENERAL.—The term ‘predictive
11 genetic information’ means, in the absence of
12 symptoms, clinical signs, or a diagnosis of the
13 condition related to such information—

14 “(i) information about an individual’s
15 genetic tests;

16 “(ii) information about genetic tests
17 of family members of the individual; or

18 “(iii) information about the occur-
19 rence of a disease or disorder in family
20 members.

21 “(B) EXCEPTIONS.—The term ‘predictive
22 genetic information’ shall not include—

23 “(i) information about the sex or age
24 of the individual;

1 “(ii) information derived from phys-
2 ical tests, such as the chemical, blood, or
3 urine analyses of the individual including
4 cholesterol tests; and

5 “(iii) information about physical
6 exams of the individual.

7 “(19) GENETIC TEST.—The term ‘genetic test’
8 means the analysis of human DNA, RNA, chro-
9 mosomes, proteins, and certain metabolites, includ-
10 ing analysis of genotypes, mutations, phenotypes, or
11 karyotypes, for the purpose of predicting risk of dis-
12 ease in asymptomatic or undiagnosed individuals.
13 Such term does not include physical tests, such as
14 the chemical, blood, or urine analyses of the indi-
15 vidual including cholesterol tests, and physical exams
16 of the individual, in order to detect symptoms, clin-
17 ical signs, or a diagnosis of disease.”.

18 (b) AMENDMENT RELATING TO THE INDIVIDUAL
19 MARKET.—The first subpart 3 of part B of title XXVII
20 of the Public Health Service Act (42 U.S.C. 300gg–51 et
21 seq.) (relating to other requirements) is amended—

22 (1) by redesignating such subpart as subpart 2;

23 and

24 (2) by adding at the end the following:

1 **“SEC. 2753. PROHIBITION OF HEALTH DISCRIMINATION ON**
2 **THE BASIS OF PREDICTIVE GENETIC INFOR-**
3 **MATION.**

4 “(a) PROHIBITION ON PREDICTIVE GENETIC INFOR-
5 MATION AS A CONDITION OF ELIGIBILITY.—A health in-
6 surance issuer offering health insurance coverage in the
7 individual market may not use predictive genetic informa-
8 tion as a condition of eligibility of an individual to enroll
9 in individual health insurance coverage (including infor-
10 mation about a request for or receipt of genetic services).

11 “(b) PROHIBITION ON PREDICTIVE GENETIC INFOR-
12 MATION IN SETTING PREMIUM RATES.—A health insur-
13 ance issuer offering health insurance coverage in the indi-
14 vidual market shall not adjust premium rates for individ-
15 uals on the basis of predictive genetic information con-
16 cerning such an enrollee or a family member of the en-
17 rollee (including information about a request for or receipt
18 of genetic services).

19 “(c) COLLECTION OF PREDICTIVE GENETIC INFOR-
20 MATION.—

21 “(1) LIMITATION ON REQUESTING OR REQUIR-
22 ING PREDICTIVE GENETIC INFORMATION.—Except
23 as provided in paragraph (2), a health insurance
24 issuer offering health insurance coverage in the indi-
25 vidual market shall not request or require predictive
26 genetic information concerning an individual or a

1 family member of the individual (including informa-
2 tion about a request for or receipt of genetic serv-
3 ices).

4 “(2) INFORMATION NEEDED FOR DIAGNOSIS,
5 TREATMENT, OR PAYMENT.—

6 “(A) IN GENERAL.—Notwithstanding para-
7 graph (1), a health insurance issuer offering
8 health insurance coverage in the individual mar-
9 ket that provides health care items and services
10 to an individual or dependent may request (but
11 may not require) that such individual or de-
12 pendent disclose, or authorize the collection or
13 disclosure of, predictive genetic information for
14 purposes of diagnosis, treatment, or payment
15 relating to the provision of health care items
16 and services to such individual or dependent.

17 “(B) NOTICE OF CONFIDENTIALITY PRAC-
18 TICES AND DESCRIPTION OF SAFEGUARDS.—As
19 a part of a request under subparagraph (A),
20 the health insurance issuer offering health in-
21 surance coverage in the individual market shall
22 provide to the individual or dependent a de-
23 scription of the procedures in place to safe-
24 guard the confidentiality, as described in sub-

1 section (d), of such predictive genetic informa-
2 tion.

3 “(d) CONFIDENTIALITY WITH RESPECT TO PRE-
4 DICTIVE GENETIC INFORMATION.—

5 “(1) NOTICE OF CONFIDENTIALITY PRAC-
6 TICES.—A health insurance issuer offering health in-
7 surance coverage in the individual market shall post
8 or provide, in writing and in a clear and conspicuous
9 manner, notice of the issuer’s confidentiality prac-
10 tices, that shall include—

11 “(A) a description of an individual’s rights
12 with respect to predictive genetic information;

13 “(B) the procedures established by the
14 issuer for the exercise of the individual’s rights;
15 and

16 “(C) the right to obtain a copy of the no-
17 tice of the confidentiality practices required
18 under this subsection.

19 “(2) ESTABLISHMENT OF SAFEGUARDS.—A
20 health insurance issuer offering health insurance
21 coverage in the individual market shall establish and
22 maintain appropriate administrative, technical, and
23 physical safeguards to protect the confidentiality, se-
24 curity, accuracy, and integrity of predictive genetic

1 information created, received, obtained, maintained,
2 used, transmitted, or disposed of by such issuer.

3 “(3) COMPLIANCE WITH CERTAIN STAND-
4 ARDS.—With respect to the establishment and main-
5 tenance of safeguards under this subsection or sub-
6 section (c)(2)(B), a group health plan, or a health
7 insurance issuer offering health insurance coverage
8 in connection with a group health plan, shall be
9 deemed to be in compliance with such subsections if
10 such plan or issuer is in compliance with the stand-
11 ards promulgated by the Secretary of Health and
12 Human Services under—

13 “(A) part C of title XI of the Social Secu-
14 rity Act (42 U.S.C. 1320d et seq.); or

15 “(B) section 264(c) of Health Insurance
16 Portability and Accountability Act of 1996
17 (Public Law 104–191; 110 Stat. 2033).”.

18 (c) EFFECTIVE DATE.—The amendments made by
19 this section shall apply with respect to—

20 (1) group health plans, and health insurance
21 coverage offered in connection with group health
22 plans, for plan years beginning after 1 year after the
23 date of enactment of this Act; and

24 (2) health insurance coverage offered, sold,
25 issued, renewed, in effect, or operated in the indi-

1 vidual market after 1 year after the date of enact-
2 ment of this Act.

3 **SEC. 4. AMENDMENTS TO THE INTERNAL REVENUE CODE**
4 **OF 1986.**

5 (a) PROHIBITION OF HEALTH DISCRIMINATION ON
6 THE BASIS OF GENETIC INFORMATION OR GENETIC
7 SERVICES.—

8 (1) NO ENROLLMENT RESTRICTION FOR GE-
9 NETIC SERVICES.—Section 9802(a)(1)(F) of the In-
10 ternal Revenue Code of 1986 is amended by insert-
11 ing before the period the following: “(including in-
12 formation about a request for or receipt of genetic
13 services)”.

14 (2) NO DISCRIMINATION IN GROUP PREMIUMS
15 BASED ON PREDICTIVE GENETIC INFORMATION.—

16 (A) IN GENERAL.—Subchapter B of chap-
17 ter 100 of the Internal Revenue Code of 1986
18 is amended by adding at the end the following:

19 **“SEC. 9813. PROHIBITING PREMIUM DISCRIMINATION**
20 **AGAINST GROUPS ON THE BASIS OF PRE-**
21 **DICTIVE GENETIC INFORMATION.**

22 “A group health plan shall not adjust premium or
23 contribution amounts for a group on the basis of predictive
24 genetic information concerning an individual in the group

1 or a family member of the individual (including informa-
2 tion about a request for or receipt of genetic services).”.

3 (B) CONFORMING AMENDMENT.—Section
4 9802(b) of the Internal Revenue Code of 1986
5 is amended by adding at the end the following:

6 “(3) REFERENCE TO RELATED PROVISION.—
7 For a provision prohibiting the adjustment of pre-
8 mium or contribution amounts for a group under a
9 group health plan on the basis of predictive genetic
10 information (including information about a request
11 for or the receipt of genetic services), see section
12 9813.”.

13 (C) AMENDMENT TO TABLE OF SEC-
14 TIONS.—The table of sections for subchapter B
15 of chapter 100 of the Internal Revenue Code of
16 1986 is amended by adding at the end the fol-
17 lowing:

“Sec. 9813. Prohibiting premium discrimination against groups on the basis of
predictive genetic information.”.

18 (b) LIMITATION ON COLLECTION OF PREDICTIVE
19 GENETIC INFORMATION.—Section 9802 of the Internal
20 Revenue Code of 1986 is amended by adding at the end
21 the following:

22 “(d) COLLECTION OF PREDICTIVE GENETIC INFOR-
23 MATION.—

1 “(1) LIMITATION ON REQUESTING OR REQUIR-
2 ING PREDICTIVE GENETIC INFORMATION.—Except
3 as provided in paragraph (2), a group health plan
4 shall not request or require predictive genetic infor-
5 mation concerning an individual or a family member
6 of the individual (including information about a re-
7 quest for or receipt of genetic services).

8 “(2) INFORMATION NEEDED FOR DIAGNOSIS,
9 TREATMENT, OR PAYMENT.—

10 “(A) IN GENERAL.—Notwithstanding para-
11 graph (1), a group health plan that provides
12 health care items and services to an individual
13 or dependent may request (but may not re-
14 quire) that such individual or dependent dis-
15 close, or authorize the collection or disclosure
16 of, predictive genetic information for purposes
17 of diagnosis, treatment, or payment relating to
18 the provision of health care items and services
19 to such individual or dependent.

20 “(B) NOTICE OF CONFIDENTIALITY PRAC-
21 TICES; DESCRIPTION OF SAFEGUARDS.—As a
22 part of a request under subparagraph (A), the
23 group health plan shall provide to the individual
24 or dependent a description of the procedures in
25 place to safeguard the confidentiality, as de-

1 scribed in subsection (e), of such predictive ge-
2 netic information.

3 “(e) CONFIDENTIALITY WITH RESPECT TO PRE-
4 DICTIVE GENETIC INFORMATION.—

5 “(1) NOTICE OF CONFIDENTIALITY PRAC-
6 TICES.—A group health plan shall post or provide,
7 in writing and in a clear and conspicuous manner,
8 notice of the plan’s confidentiality practices, that
9 shall include—

10 “(A) a description of an individual’s rights
11 with respect to predictive genetic information;

12 “(B) the procedures established by the
13 plan for the exercise of the individual’s rights;
14 and

15 “(C) the right to obtain a copy of the no-
16 tice of the confidentiality practices required
17 under this subsection.

18 “(2) ESTABLISHMENT OF SAFEGUARDS.—A
19 group health plan shall establish and maintain ap-
20 propriate administrative, technical, and physical
21 safeguards to protect the confidentiality, security,
22 accuracy, and integrity of predictive genetic informa-
23 tion created, received, obtained, maintained, used,
24 transmitted, or disposed of by such plan.

1 “(3) COMPLIANCE WITH CERTAIN STAND-
2 ARDS.—With respect to the establishment and main-
3 tenance of safeguards under this subsection or sub-
4 section (d)(2)(B), a group health plan, or a health
5 insurance issuer offering health insurance coverage
6 in connection with a group health plan, shall be
7 deemed to be in compliance with such subsections if
8 such plan or issuer is in compliance with the stand-
9 ards promulgated by the Secretary of Health and
10 Human Services under—

11 “(A) part C of title XI of the Social Secu-
12 rity Act (42 U.S.C. 1320d et seq.); or

13 “(B) section 264(c) of Health Insurance
14 Portability and Accountability Act of 1996
15 (Public Law 104–191; 110 Stat. 2033).”.

16 (c) DEFINITIONS.—Section 9832(d) of the Internal
17 Revenue Code of 1986 is amended by adding at the end
18 the following:

19 “(6) FAMILY MEMBER.—The term ‘family
20 member’ means, with respect to an individual—

21 “(A) the spouse of the individual;

22 “(B) a dependent child of the individual,
23 including a child who is born to or placed for
24 adoption with the individual; and

1 “(C) all other individuals related by blood
2 to the individual or the spouse or child de-
3 scribed in subparagraph (A) or (B).

4 “(7) 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 (in-
8 cluding information about a request for or receipt of
9 genetic services).

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

15 “(9) PREDICTIVE GENETIC INFORMATION.—

16 “(A) IN GENERAL.—The term ‘predictive
17 genetic information’ means, in the absence of
18 symptoms, clinical signs, or a diagnosis of the
19 condition related to such information—

20 “(i) information about an individual’s
21 genetic tests;

22 “(ii) information about genetic tests
23 of family members of the individual; or

1 “(iii) information about the occur-
2 rence of a disease or disorder in family
3 members.

4 “(B) EXCEPTIONS.—The term ‘predictive
5 genetic information’ shall not include—

6 “(i) information about the sex or age
7 of the individual;

8 “(ii) information derived from phys-
9 ical tests, such as the chemical, blood, or
10 urine analyses of the individual including
11 cholesterol tests; and

12 “(iii) information about physical
13 exams of the individual.

14 “(10) GENETIC TEST.—The term ‘genetic test’
15 means the analysis of human DNA, RNA, chro-
16 mosomes, proteins, and certain metabolites, includ-
17 ing analysis of genotypes, mutations, phenotypes, or
18 karyotypes, for the purpose of predicting risk of dis-
19 ease in asymptomatic or undiagnosed individuals.
20 Such term does not include physical tests, such as
21 the chemical, blood, or urine analyses of the indi-
22 vidual including cholesterol tests, and physical exams
23 of the individual, in order to detect symptoms, clin-
24 ical signs, or a diagnosis of disease.”.

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

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