

106TH CONGRESS
1ST SESSION

S. 543

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

IN THE SENATE OF THE UNITED STATES

MARCH 4, 1999

Ms. SNOWE (for herself, Mr. FRIST, Mr. JEFFORDS, Mr. HAGEL, Ms. COLLINS, 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 1999”.

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

8 (a) PROHIBITION OF HEALTH DISCRIMINATION ON
9 THE BASIS OF GENETIC INFORMATION OR GENETIC
10 SERVICES.—

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

8 (2) NO DISCRIMINATION IN GROUP PREMIUMS
 9 BASED ON PREDICTIVE GENETIC INFORMATION.—
 10 Subpart B of part 7 of subtitle B of title I of the
 11 Employee Retirement Income Security Act of 1974,
 12 as amended by the Omnibus Consolidated and
 13 Emergency Supplemental Appropriations Act, 1999
 14 (Public Law 105–277), is amended by adding at the
 15 end the following:

16 **“SEC. 714. PROHIBITING PREMIUM DISCRIMINATION**
 17 **AGAINST GROUPS ON THE BASIS OF PRE-**
 18 **DICTIVE GENETIC INFORMATION.**

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

1 (3) CONFORMING AMENDMENTS.—

2 (A) IN GENERAL.—Section 702(b) of the
3 Employee Retirement Income Security Act of
4 1974 (29 U.S.C. 1182(b)) is amended by add-
5 ing 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 receipt of genetic services), see section 714.”.

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

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

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

21 “(c) COLLECTION OF PREDICTIVE GENETIC INFOR-
22 MATION.—

23 “(1) LIMITATION ON REQUESTING OR REQUIR-
24 ING PREDICTIVE GENETIC INFORMATION.—Except

1 as provided in paragraph (2), a group health plan,
2 or a health insurance issuer offering health insur-
3 ance coverage in connection with a group health
4 plan, shall not request or require predictive genetic
5 information concerning an individual or a family
6 member of the individual (including information
7 about a request 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, or a health in-
12 surance issuer offering health insurance cov-
13 erage in connection with a group health plan,
14 that provides health care items and services to
15 an individual or dependent may request (but
16 may not require) that such individual or de-
17 pendent disclose, or authorize the collection or
18 disclosure of, predictive genetic information for
19 purposes of diagnosis, treatment, or payment
20 relating to the provision of health care items
21 and services to such individual or dependent.

22 “(B) NOTICE OF CONFIDENTIALITY PRAC-
23 TICES AND DESCRIPTION OF SAFEGUARDS.—As
24 a part of a request under subparagraph (A),
25 the group health plan, or a health insurance

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

7 “(d) CONFIDENTIALITY WITH RESPECT TO PRE-
8 DICTIVE GENETIC INFORMATION.—

9 “(1) NOTICE OF CONFIDENTIALITY PRAC-
10 TICES.—

11 “(A) PREPARATION OF WRITTEN NO-
12 TICE.—A group health plan, or a health insur-
13 ance issuer offering health insurance coverage
14 in connection with a group health plan, shall
15 post or provide, in writing and in a clear and
16 conspicuous manner, notice of the plan or
17 issuer’s confidentiality practices, that shall
18 include—

19 “(i) a description of an individual’s
20 rights with respect to predictive genetic in-
21 formation;

22 “(ii) the procedures established by the
23 plan or issuer for the exercise of the indi-
24 vidual’s rights; and

1 “(iii) the right to obtain a copy of the
2 notice of the confidentiality practices re-
3 quired under this subsection.

4 “(B) MODEL NOTICE.—The Secretary, in
5 consultation with the National Committee on
6 Vital and Health Statistics and the National
7 Association of Insurance Commissioners, and
8 after notice and opportunity for public com-
9 ment, shall develop and disseminate model no-
10 tices of confidentiality practices. Use of the
11 model notice shall serve as a defense against
12 claims of receiving inappropriate notice.

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

22 (c) DEFINITIONS.—Section 733(d) of the Employee
23 Retirement Income Security Act of 1974 (29 U.S.C.
24 1191b(d)) is amended by adding at the end the following:

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

3 “(A) the spouse of the individual;

4 “(B) a dependent child of the individual,
5 including a child who is born to or placed for
6 adoption with the individual; and

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

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

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

21 “(8) PREDICTIVE GENETIC INFORMATION.—

22 “(A) IN GENERAL.—The term ‘predictive
23 genetic information’ means, in the absence of
24 symptoms, clinical signs, or a diagnosis of the
25 condition related to such information—

1 “(i) information about an individual’s
2 genetic tests;

3 “(ii) information about genetic tests
4 of family members of the individual; or

5 “(iii) information about the occur-
6 rence of a disease or disorder in family
7 members.

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

10 “(i) information about the sex or age
11 of the individual;

12 “(ii) information derived from phys-
13 ical tests, such as the chemical, blood, or
14 urine analyses of the individual including
15 cholesterol tests; and

16 “(iii) information about physical
17 exams of the individual.

18 “(9) GENETIC TEST.—The term ‘genetic test’
19 means the analysis of human DNA, RNA, chro-
20 mosomes, proteins, and certain metabolites, includ-
21 ing analysis of genotypes, mutations, phenotypes, or
22 karyotypes, for the purpose of predicting risk of dis-
23 ease in asymptomatic or undiagnosed individuals.”.

24 (d) EFFECTIVE DATE.—Except as provided in this
25 section, this section and the amendments made by this

1 section shall apply with respect to group health plans for
2 plan years beginning 1 year after the date of the enact-
3 ment of this Act.

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

6 (a) AMENDMENTS RELATING TO THE GROUP MAR-
7 KET.—

8 (1) PROHIBITION OF HEALTH DISCRIMINATION
9 ON THE BASIS OF GENETIC INFORMATION IN THE
10 GROUP MARKET.—

11 (A) NO ENROLLMENT RESTRICTION FOR
12 GENETIC SERVICES.—Section 2702(a)(1)(F) of
13 the Public Health Service Act (42 U.S.C.
14 300gg–1(a)(1)(F)) is amended by inserting be-
15 fore the period the following: “(including infor-
16 mation about a request for or receipt of genetic
17 services)”.

18 (B) NO DISCRIMINATION IN PREMIUMS
19 BASED ON PREDICTIVE GENETIC INFORMA-
20 TION.—Subpart 2 of part A of title XXVII of
21 the Public Health Service Act, as amended by
22 the Omnibus Consolidated and Emergency Sup-
23 plemental Appropriations Act, 1999 (Public
24 Law 105–277), is amended by adding at the
25 end the following new section:

1 **“SEC. 2707. PROHIBITING PREMIUM DISCRIMINATION**
 2 **AGAINST GROUPS ON THE BASIS OF PRE-**
 3 **DICTIVE GENETIC INFORMATION IN THE**
 4 **GROUP MARKET.**

5 “A group health plan, or a health insurance issuer
 6 offering group health insurance coverage in connection
 7 with a group health plan shall not adjust premium or con-
 8 tribution amounts for a group on the basis of predictive
 9 genetic information concerning an individual in the group
 10 or a family member of the individual (including informa-
 11 tion about a request for or receipt of genetic services).”.

12 (C) CONFORMING AMENDMENT.—Section
 13 2702(b) of the Public Health Service Act (42
 14 U.S.C. 300gg–1(b)) is amended by adding at
 15 the end the following:

16 “(3) REFERENCE TO RELATED PROVISION.—
 17 For a provision prohibiting the adjustment of pre-
 18 mium or contribution amounts for a group under a
 19 group health plan on the basis of predictive genetic
 20 information (including information about a request
 21 for or receipt of genetic services), see section 2707.”.

22 (D) LIMITATION ON COLLECTION AND DIS-
 23 CLOSURE OF PREDICTIVE GENETIC INFORMA-
 24 TION.—Section 2702 of the Public Health Serv-
 25 ice Act (42 U.S.C. 300gg–1) is amended by
 26 adding at the end the following:

1 “(c) COLLECTION OF PREDICTIVE GENETIC INFOR-
2 MATION.—

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

12 “(2) INFORMATION NEEDED FOR DIAGNOSIS,
13 TREATMENT, OR PAYMENT.—

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

1 “(B) NOTICE OF CONFIDENTIALITY PRAC-
2 TICES AND DESCRIPTION OF SAFEGUARDS.—As
3 a part of a request under subparagraph (A),
4 the group health plan, or a health insurance
5 issuer offering health insurance coverage in
6 connection with a group health plan, shall pro-
7 vide to the individual or dependent a descrip-
8 tion of the procedures in place to safeguard the
9 confidentiality, as described in subsection (d),
10 of such predictive genetic information.

11 “(d) CONFIDENTIALITY WITH RESPECT TO PRE-
12 DICTIVE GENETIC INFORMATION.—

13 “(1) NOTICE OF CONFIDENTIALITY PRAC-
14 TICES.—

15 “(A) PREPARATION OF WRITTEN NO-
16 TICE.—A group health plan, or a health insur-
17 ance issuer offering health insurance coverage
18 in connection with a group health plan, shall
19 post or provide, in writing and in a clear and
20 conspicuous manner, notice of the plan or
21 issuer’s confidentiality practices, that shall
22 include—

23 “(i) a description of an individual’s
24 rights with respect to predictive genetic in-
25 formation;

1 “(ii) the procedures established by the
2 plan or issuer for the exercise of the indi-
3 vidual’s rights; and

4 “(iii) the right to obtain a copy of the
5 notice of the confidentiality practices re-
6 quired under this subsection.

7 “(B) MODEL NOTICE.—The Secretary, in
8 consultation with the National Committee on
9 Vital and Health Statistics and the National
10 Association of Insurance Commissioners, and
11 after notice and opportunity for public com-
12 ment, shall develop and disseminate model no-
13 tices of confidentiality practices. Use of the
14 model notice shall serve as a defense against
15 claims of receiving inappropriate notice.

16 “(2) ESTABLISHMENT OF SAFEGUARDS.—A
17 group health plan, or a health insurance issuer offer-
18 ing health insurance coverage in connection with 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 or issuer.”.

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

4 “(15) 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 “(16) 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 “(17) 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 “(18) 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 “(19) 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 (b) AMENDMENT RELATING TO THE INDIVIDUAL
 4 MARKET.—The first subpart 3 of part B of title XXVII
 5 of the Public Health Service Act (42 U.S.C. 300gg–51 et
 6 seq.) (relating to other requirements), as amended by the
 7 Omnibus Consolidated and Emergency Supplemental Ap-
 8 propriations Act, 1999 (Public Law 105–277) is
 9 amended—

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

11 and

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

13 **“SEC. 2753. PROHIBITION OF HEALTH DISCRIMINATION ON**
 14 **THE BASIS OF PREDICTIVE GENETIC INFOR-**
 15 **MATION.**

16 “(a) PROHIBITION ON PREDICTIVE GENETIC INFOR-
 17 MATION AS A CONDITION OF ELIGIBILITY.—A health in-
 18 surance issuer offering health insurance coverage in the
 19 individual market may not use predictive genetic informa-
 20 tion as a condition of eligibility of an individual to enroll
 21 in individual health insurance coverage (including infor-
 22 mation about a request for or receipt of genetic services).

23 “(b) PROHIBITION ON PREDICTIVE GENETIC INFOR-
 24 MATION IN SETTING PREMIUM RATES.—A health insur-
 25 ance issuer offering health insurance coverage in the indi-

1 individual market shall not adjust premium rates for individ-
2 uals on the basis of predictive genetic information concern-
3 ing such an enrollee or a family member of the enrollee
4 (including information about a request for or receipt of
5 genetic services).

6 “(c) COLLECTION OF PREDICTIVE GENETIC INFOR-
7 MATION.—

8 “(1) LIMITATION ON REQUESTING OR REQUIR-
9 ING PREDICTIVE GENETIC INFORMATION.—Except
10 as provided in paragraph (2), a health insurance
11 issuer offering health insurance coverage in the indi-
12 vidual market shall not request or require predictive
13 genetic information concerning an individual or a
14 family member of the individual (including informa-
15 tion about a request for or receipt of genetic serv-
16 ices).

17 “(2) INFORMATION NEEDED FOR DIAGNOSIS,
18 TREATMENT, OR PAYMENT.—

19 “(A) IN GENERAL.—Notwithstanding para-
20 graph (1), a health insurance issuer offering
21 health insurance coverage in the individual mar-
22 ket that provides health care items and services
23 to an individual or dependent may request (but
24 may not require) that such individual or de-
25 pendent disclose, or authorize the collection or

1 disclosure of, predictive genetic information for
2 purposes of diagnosis, treatment, or payment
3 relating to the provision of health care items
4 and services to such individual or dependent.

5 “(B) NOTICE OF CONFIDENTIALITY PRAC-
6 TICES AND DESCRIPTION OF SAFEGUARDS.—As
7 a part of a request under subparagraph (A),
8 the health insurance issuer offering health in-
9 surance coverage in the individual market shall
10 provide to the individual or dependent a de-
11 scription of the procedures in place to safe-
12 guard the confidentiality, as described in sub-
13 section (d), of such predictive genetic informa-
14 tion.

15 “(d) CONFIDENTIALITY WITH RESPECT TO PRE-
16 DICTIVE GENETIC INFORMATION.—

17 “(1) NOTICE OF CONFIDENTIALITY PRAC-
18 TICES.—

19 “(A) PREPARATION OF WRITTEN NO-
20 TICE.—A health insurance issuer offering
21 health insurance coverage in the individual mar-
22 ket shall post or provide, in writing and in a
23 clear and conspicuous manner, notice of the
24 issuer’s confidentiality practices, that shall
25 include—

1 “(i) a description of an individual’s
2 rights with respect to predictive genetic in-
3 formation;

4 “(ii) the procedures established by the
5 issuer for the exercise of the individual’s
6 rights; and

7 “(iii) the right to obtain a copy of the
8 notice of the confidentiality practices re-
9 quired under this subsection.

10 “(B) MODEL NOTICE.—The Secretary, in
11 consultation with the National Committee on
12 Vital and Health Statistics and the National
13 Association of Insurance Commissioners, and
14 after notice and opportunity for public com-
15 ment, shall develop and disseminate model no-
16 tices of confidentiality practices. Use of the
17 model notice shall serve as a defense against
18 claims of receiving inappropriate notice.

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

5 (1) group health plans, and health insurance
6 coverage offered in connection with group health
7 plans, for plan years beginning after 1 year after the
8 date of enactment of this Act; and

9 (2) health insurance coverage offered, sold,
10 issued, renewed, in effect, or operated in the individ-
11 ual market after 1 year after the date of enactment
12 of this Act.

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

15 (a) PROHIBITION OF HEALTH DISCRIMINATION ON
16 THE BASIS OF GENETIC INFORMATION OR GENETIC
17 SERVICES.—

18 (1) NO ENROLLMENT RESTRICTION FOR GE-
19 NETIC SERVICES.—Section 9802(a)(1)(F) of the In-
20 ternal Revenue Code of 1986 is amended by insert-
21 ing before the period the following: “(including in-
22 formation about a request for or receipt of genetic
23 services)”.

24 (2) NO DISCRIMINATION IN GROUP PREMIUMS
25 BASED ON PREDICTIVE GENETIC INFORMATION.—

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

4 **“SEC. 9813. PROHIBITING PREMIUM DISCRIMINATION**
 5 **AGAINST GROUPS ON THE BASIS OF PRE-**
 6 **DICTIVE GENETIC INFORMATION.**

7 “A group health plan shall not adjust premium or
 8 contribution amounts for a group on the basis of predictive
 9 genetic information concerning an individual in the group
 10 or a family member of the individual (including informa-
 11 tion about a request for or receipt of genetic services).”.

12 (B) CONFORMING AMENDMENT.—Section
 13 9802(b) of the Internal Revenue Code of 1986
 14 is amended by adding at the end the following:

15 “(3) REFERENCE TO RELATED PROVISION.—
 16 For a provision prohibiting the adjustment of pre-
 17 mium or contribution amounts for a group under a
 18 group health plan on the basis of predictive genetic
 19 information (including information about a request
 20 for or the receipt of genetic services), see section
 21 9813.”.

22 (C) AMENDMENT TO TABLE OF SEC-
 23 TIONS.—The table of sections for subchapter B
 24 of chapter 100 of the Internal Revenue Code of

1 1986 is amended by adding at the end the fol-
 2 lowing:

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

3 (b) LIMITATION ON COLLECTION OF PREDICTIVE
 4 GENETIC INFORMATION.—Section 9802 of the Internal
 5 Revenue Code of 1986 is amended by adding at the end
 6 the following:

7 “(d) COLLECTION OF PREDICTIVE GENETIC INFOR-
 8 MATION.—

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

16 “(2) INFORMATION NEEDED FOR DIAGNOSIS,
 17 TREATMENT, OR PAYMENT.—

18 “(A) IN GENERAL.—Notwithstanding para-
 19 graph (1), a group health plan that provides
 20 health care items and services to an individual
 21 or dependent may request (but may not re-
 22 quire) that such individual or dependent dis-
 23 close, or authorize the collection or disclosure
 24 of, predictive genetic information for purposes

1 of diagnosis, treatment, or payment relating to
2 the provision of health care items and services
3 to such individual or dependent.

4 “(B) NOTICE OF CONFIDENTIALITY PRAC-
5 TICES; DESCRIPTION OF SAFEGUARDS.—As a
6 part of a request under subparagraph (A), the
7 group health plan shall provide to the individual
8 or dependent a description of the procedures in
9 place to safeguard the confidentiality, as de-
10 scribed in subsection (e), of such predictive ge-
11 netic information.

12 “(e) CONFIDENTIALITY WITH RESPECT TO PRE-
13 DICTIVE GENETIC INFORMATION.—

14 “(1) NOTICE OF CONFIDENTIALITY PRAC-
15 TICES.—

16 “(A) PREPARATION OF WRITTEN NO-
17 TICE.—A group health plan shall post or pro-
18 vide, in writing and in a clear and conspicuous
19 manner, notice of the plan’s confidentiality
20 practices, that shall include—

21 “(i) a description of an individual’s
22 rights with respect to predictive genetic in-
23 formation;

1 “(ii) the procedures established by the
2 plan for the exercise of the individual’s
3 rights; and

4 “(iii) the right to obtain a copy of the
5 notice of the confidentiality practices re-
6 quired under this subsection.

7 “(B) MODEL NOTICE.—The Secretary, in
8 consultation with the National Committee on
9 Vital and Health Statistics and the National
10 Association of Insurance Commissioners, and
11 after notice and opportunity for public com-
12 ment, shall develop and disseminate model no-
13 tices of confidentiality practices. Use of the
14 model notice shall serve as a defense against
15 claims of receiving inappropriate notice.

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

23 (c) DEFINITIONS.—Section 9832(d) of the Internal
24 Revenue Code of 1986 is amended by adding at the end
25 the following:

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

3 “(A) the spouse of the individual;

4 “(B) a dependent child of the individual,
5 including a child who is born to or placed for
6 adoption with the individual; and

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

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

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

21 “(9) PREDICTIVE GENETIC INFORMATION.—

22 “(A) IN GENERAL.—The term ‘predictive
23 genetic information’ means, in the absence of
24 symptoms, clinical signs, or a diagnosis of the
25 condition related to such information—

1 “(i) information about an individual’s
2 genetic tests;

3 “(ii) information about genetic tests
4 of family members of the individual; or

5 “(iii) information about the occur-
6 rence of a disease or disorder in family
7 members.

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

10 “(i) information about the sex or age
11 of the individual;

12 “(ii) information derived from phys-
13 ical tests, such as the chemical, blood, or
14 urine analyses of the individual including
15 cholesterol tests; and

16 “(iii) information about physical
17 exams of the individual.

18 “(10) GENETIC TEST.—The term ‘genetic test’
19 means the analysis of human DNA, RNA, chro-
20 mosomes, proteins, and certain metabolites, includ-
21 ing analysis of genotypes, mutations, phenotypes, or
22 karyotypes, for the purpose of predicting risk of dis-
23 ease in asymptomatic or undiagnosed individuals.”.

24 (d) EFFECTIVE DATE.—Except as provided in this
25 section, this section and the amendments made by this

1 section shall apply with respect to group health plans for
2 plan years beginning after 1 year after the date of the
3 enactment of this Act.

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