

Calendar No. 247

108TH CONGRESS
1ST SESSION

S. 1053

[Report No. 108-122]

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

IN THE SENATE OF THE UNITED STATES

MAY 13, 2003

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

JULY 31 (legislative day, JULY 21), 2003

Reported by Mr. GREGG, with an amendment

[Strike out all after the enacting clause and insert the part printed in *italic*]

A BILL

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

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 Act of 2003~~”.

1 **TITLE I—GENETIC NON-**
 2 **DISCRIMINATION IN HEALTH**
 3 **INSURANCE**

4 **SEC. 101. AMENDMENTS TO EMPLOYEE RETIREMENT IN-**
 5 **COME SECURITY ACT OF 1974.**

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

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

16 (2) NO DISCRIMINATION IN GROUP PREMIUMS
 17 BASED ON GENETIC INFORMATION.—Section 702(b)
 18 of the Employee Retirement Income Security Act of
 19 1974 (29 U.S.C. 1182(b)) is amended by adding at
 20 the end the following:

21 “(3) NO DISCRIMINATION IN GROUP PREMIUMS
 22 BASED ON GENETIC INFORMATION.—For purposes
 23 of this section, a group health plan, or a health in-
 24 surance issuer offering group health insurance cov-
 25 erage in connection with a group health plan, shall

1 not adjust premium or contribution amounts for a
2 group on the basis of genetic information concerning
3 an individual in the group or a family member of the
4 individual (including information about a request for
5 or receipt of genetic services).

6 (b) LIMITATIONS ON GENETIC TESTING AND THE
7 COLLECTION OF GENETIC INFORMATION.—Section 702 of
8 the Employee Retirement Income Security Act of 1974
9 (29 U.S.C. 1182) is amended by adding at the end the
10 following:

11 “(c) GENETIC TESTING.—

12 “(1) LIMITATION ON REQUESTING OR REQUIR-
13 ING GENETIC TESTING.—A group health plan, or a
14 health insurance issuer offering health insurance
15 coverage in connection with a group health plan,
16 shall not request or require an individual or a family
17 member of such individual to undergo a genetic test.

18 “(2) RULE OF CONSTRUCTION.—Nothing in
19 this part shall be construed to limit the authority of
20 a health care professional, who is providing health
21 care services with respect to an individual or who is
22 acting on behalf of a group health plan or a health
23 insurance issuer, to request that such individual or
24 a family member of such individual undergo a ge-
25 netic test. Such a health care professional shall not

1 require that such individual or family member un-
 2 dergo a genetic test.

3 “(d) COMPLIANCE WITH CERTAIN CONFIDENTIALITY
 4 STANDARDS WITH RESPECT TO GENETIC INFORMA-
 5 TION.—With respect to the use or disclosure of genetic
 6 information by a group health plan, or a health insurance
 7 issuer offering health insurance coverage in connection
 8 with a group health plan, such information shall be
 9 deemed to be protected health information for purposes
 10 of, and shall be subject to, the standards promulgated by
 11 the Secretary of Health and Human Services under—

12 “(1) part C of title XI of the Social Security
 13 Act (42 U.S.C. 1320d et seq.); or

14 “(2) section 264(e) of the Health Insurance
 15 Portability and Accountability Act of 1996 (Public
 16 Law 104–191; 110 Stat. 2033).

17 “(e) COLLECTION OF GENETIC INFORMATION.—

18 “(1) LIMITATION ON REQUESTING OR REQUIR-
 19 ING GENETIC INFORMATION.—Except as provided in
 20 paragraph (2), a group health plan, or a health in-
 21 surance issuer offering health insurance coverage in
 22 connection with a group health plan, shall not re-
 23 quest or require genetic information concerning an
 24 individual or a family member of the individual (in-

1 eluding information about a request for or receipt of
2 genetic services).

3 ~~“(2) INFORMATION NEEDED FOR TREATMENT,~~
4 ~~PAYMENT, AND HEALTH CARE OPERATIONS.—Not-~~
5 ~~withstanding paragraph (1), a group health plan, or~~
6 ~~a health insurance issuer offering health insurance~~
7 ~~coverage in connection with a group health plan,~~
8 ~~that provides health care items and services to an in-~~
9 ~~dividual may request genetic information concerning~~
10 ~~such individual or dependent for purposes of treat-~~
11 ~~ment, payment, or health care operations in accord-~~
12 ~~ance with the standards for protected health infor-~~
13 ~~mation described in subsection (d) to the extent that~~
14 ~~the use of such information is otherwise consistent~~
15 ~~with this section.~~

16 ~~“(3) FAILURE TO PROVIDE NECESSARY INFOR-~~
17 ~~MATION.—If an individual or dependent refuses to~~
18 ~~provide the information requested under paragraph~~
19 ~~(2), and such information is for treatment, payment,~~
20 ~~or health care operations relating to the individual,~~
21 ~~the group health plan or health insurance issuer re-~~
22 ~~questing such information shall not be required to~~
23 ~~provide coverage for the items, services, or treat-~~
24 ~~ments with respect to which the requested informa-~~
25 ~~tion relates in any action under part 5.”.~~

1 (e) 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.—

14 “(A) IN GENERAL.—Except as provided in
15 subparagraph (B), the term ‘genetic informa-
16 tion’ means information—

17 “(i) concerning—

18 “(I) the genetic tests of an indi-
19 vidual;

20 “(II) the genetic tests of family
21 members of the individual; or

22 “(III) the occurrence of a disease
23 or disorder in family members of the
24 individual; and

1 “(ii) that is used to predict risk of
2 disease in asymptomatic or undiagnosed
3 individuals.

4 “(B) EXCEPTIONS.—The term ‘genetic in-
5 formation’ shall not include—

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

8 “(ii) information derived from clinical
9 and laboratory tests, such as the chemical,
10 blood, or urine analyses of the individual
11 including cholesterol tests, used to deter-
12 mine health status or detect illness or diag-
13 nose disease; and

14 “(iii) information about physical
15 exams of the individual.

16 “(7) GENETIC SERVICES.—The term ‘genetic
17 services’ means health services provided for genetic
18 education and counseling.

19 “(8) GENETIC TEST.—The term ‘genetic test’
20 means the analysis of human DNA, RNA, chro-
21 mosomes, proteins, and metabolites, that detect
22 genotypes, mutations, or chromosomal changes.
23 Such term does not include information described in
24 paragraph (6)(B).”.

25 (d) REGULATIONS AND EFFECTIVE DATE.—

1 (1) REGULATIONS.—Not later than 1 year after
 2 the date of enactment of this title, the Secretary of
 3 Labor shall issue final regulations in an accessible
 4 format to carry out the amendments made by this
 5 section.

6 (2) EFFECTIVE DATE.—The amendments made
 7 by this section shall apply with respect to group
 8 health plans for plan years beginning after the date
 9 that is 18 months after the date of enactment of
 10 this title.

11 **SEC. 102. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**

12 **ACT.**

13 (a) AMENDMENTS RELATING TO THE GROUP MAR-
 14 KET.—

15 (1) PROHIBITION OF HEALTH DISCRIMINATION
 16 ON THE BASIS OF GENETIC INFORMATION OR GE-
 17 NETIC SERVICES.—

18 (A) NO ENROLLMENT RESTRICTION FOR
 19 GENETIC SERVICES.—Section 2702(a)(1)(F) of
 20 the Public Health Service Act (42 U.S.C.
 21 300gg-1(a)(1)(F)) is amended by inserting be-
 22 fore the period the following: “(including infor-
 23 mation about a request for or receipt of genetic
 24 services)”.

1 ~~(B) NO DISCRIMINATION IN GROUP PRE-~~
 2 ~~MIUMS BASED ON GENETIC INFORMATION.—~~
 3 Section 2702(b) of the Public Health Service
 4 Act (~~42 U.S.C. 300gg-1(b)~~) is amended by
 5 adding at the end the following:

6 ~~“(3) NO DISCRIMINATION IN GROUP PREMIUMS~~
 7 ~~BASED ON GENETIC INFORMATION.—~~For purposes
 8 of this section, a group health plan, or a health in-
 9 surance issuer offering group health insurance cov-
 10 erage in connection with a group health plan, shall
 11 not adjust premium or contribution amounts for a
 12 group on the basis of genetic information concerning
 13 an individual in the group or a family member of the
 14 individual (including information about a request for
 15 or receipt of genetic services).”.

16 (2) ~~LIMITATIONS ON GENETIC TESTING AND~~
 17 ~~THE COLLECTION OF GENETIC INFORMATION.—~~Sec-
 18 tion 2702 of the Public Health Service Act (~~42~~
 19 ~~U.S.C. 300gg-1~~) is amended by adding at the end
 20 the following:

21 ~~“(c) GENETIC TESTING.—~~

22 ~~“(1) LIMITATION ON REQUESTING OR REQUIR-~~
 23 ~~ING GENETIC TESTING.—~~A group health plan, or a
 24 health insurance issuer offering health insurance
 25 coverage in connection with a group health plan,

1 shall not request or require an individual or a family
2 member of such individual to undergo a genetic test.

3 “(2) RULE OF CONSTRUCTION.—Nothing in
4 this part shall be construed to limit the authority of
5 a health care professional, who is providing health
6 care services with respect to an individual or who is
7 acting on behalf of a group health plan or a health
8 insurance issuer, to request that such individual or
9 a family member of such individual undergo a ge-
10 netic test. Such a health care professional shall not
11 require that such individual or family member un-
12 dergo a genetic test.

13 “(d) COMPLIANCE WITH CERTAIN CONFIDENTIALITY
14 STANDARDS WITH RESPECT TO GENETIC INFORMA-
15 TION.—With respect to the use or disclosure of genetic
16 information by a group health plan, or a health insurance
17 issuer offering health insurance coverage in connection
18 with a group health plan, such information shall be
19 deemed to be protected health information for purposes
20 of, and shall be subject to, the standards promulgated by
21 the Secretary of Health and Human Services under—

22 “(1) part C of title XI of the Social Security
23 Act (42 U.S.C. 1320d et seq.); or

1 ~~“(2) section 264(c) of the Health Insurance~~
2 ~~Portability and Accountability Act of 1996 (Public~~
3 ~~Law 104-191; 110 Stat. 2033).~~

4 ~~“(e) COLLECTION OF GENETIC INFORMATION.—~~

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

14 ~~“(2) INFORMATION NEEDED FOR TREATMENT,~~
15 ~~PAYMENT, AND HEALTH CARE OPERATIONS.—Not-~~
16 ~~withstanding paragraph (1), a group health plan, or~~
17 ~~a health insurance issuer offering health insurance~~
18 ~~coverage in connection with a group health plan,~~
19 ~~that provides health care items and services to an in-~~
20 ~~dividual may request genetic information concerning~~
21 ~~such individual or dependent for purposes of treat-~~
22 ~~ment, payment, or health care operations in accord-~~
23 ~~ance with the standards for protected health infor-~~
24 ~~mation described in subsection (d) to the extent that~~

1 the use of such information is otherwise consistent
2 with this section.

3 ~~“(3) FAILURE TO PROVIDE NECESSARY INFOR-~~
4 ~~MATION.—If an individual or dependent refuses to~~
5 ~~provide the information requested under paragraph~~
6 ~~(2), and such information is for treatment, payment,~~
7 ~~or health care operations relating to the individual,~~
8 ~~the group health plan or health insurance issuer re-~~
9 ~~questing such information shall not be required to~~
10 ~~provide coverage for the items, services, or treat-~~
11 ~~ments with respect to which the requested informa-~~
12 ~~tion relates.”.~~

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

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

18 ~~“(A) the spouse of the individual;~~

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

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

25 ~~“(16) GENETIC INFORMATION.—~~

1 “(A) IN GENERAL.—Except as provided in
2 subparagraph (B), the term ‘genetic informa-
3 tion’ means information—

4 “(i) concerning—

5 “(I) the genetic tests of an indi-
6 vidual;

7 “(II) the genetic tests of family
8 members of the individual; or

9 “(III) the occurrence of a disease
10 or disorder in family members of the
11 individual; and

12 “(ii) that is used to predict risk of
13 disease in asymptomatic or undiagnosed
14 individuals.

15 “(B) EXCEPTIONS.—The term ‘genetic in-
16 formation’ shall not include—

17 “(i) information about the sex or age
18 of the individual;

19 “(ii) information derived from clinical
20 and laboratory tests, such as the chemical,
21 blood, or urine analyses of the individual
22 including cholesterol tests, used to deter-
23 mine health status or detect illness or diag-
24 nose disease; and

1 “(iii) information about physical
2 exams of the individual.

3 “(17) GENETIC SERVICES.—The term ‘genetic
4 services’ means health services provided for genetic
5 education and counseling.

6 “(18) GENETIC TEST.—The term ‘genetic test’
7 means the analysis of human DNA, RNA, chro-
8 mosomes, proteins, and metabolites, that detect
9 genotypes, mutations, or chromosomal changes.
10 Such term does not include information described in
11 paragraph (16)(B).”.

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

16 (1) by redesignating such subpart as subpart 2;
17 and

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

19 “**SEC. 2753. PROHIBITION OF HEALTH DISCRIMINATION ON**
20 **THE BASIS OF GENETIC INFORMATION.**

21 “(a) PROHIBITION ON GENETIC INFORMATION AS A
22 CONDITION OF ELIGIBILITY.—A health insurance issuer
23 offering health insurance coverage in the individual mar-
24 ket may not use genetic information as a condition of eligi-
25 bility of an individual to enroll in individual health insur-

1 ance coverage (including information about a request for
2 or receipt of genetic services).

3 “(b) PROHIBITION ON GENETIC INFORMATION IN
4 SETTING PREMIUM RATES.—For purposes of this section,
5 a health insurance issuer offering health insurance cov-
6 erage in the individual market shall not adjust premium
7 or contribution amounts for an individual on the basis of
8 genetic information concerning the individual or a family
9 member of the individual (including information about a
10 request for or receipt of genetic services).

11 “(c) GENETIC TESTING.—

12 “(1) LIMITATION ON REQUESTING OR REQUIR-
13 ING GENETIC TESTING.—A health insurance issuer
14 offering health insurance coverage in the individual
15 market shall not request or require an individual or
16 a family member of such individual to undergo a ge-
17 netic test.

18 “(2) RULE OF CONSTRUCTION.—Nothing in
19 this part shall be construed to limit the authority of
20 a health care professional, who is providing health
21 care services with respect to an individual or who is
22 acting on behalf of a health insurance issuer, to re-
23 quest that such individual or a family member of
24 such individual undergo a genetic test. Such a health

1 care professional shall not require that such indi-
2 vidual or family member undergo a genetic test.

3 “(d) COMPLIANCE WITH CERTAIN CONFIDENTIALITY
4 STANDARDS WITH RESPECT TO GENETIC INFORMA-
5 TION.—With respect to the use or disclosure of genetic
6 information by a health insurance issuer offering health
7 insurance coverage in the individual market, such informa-
8 tion shall be deemed to be protected health information
9 for purposes of, and shall be subject to, the standards pro-
10 mulgated by the Secretary of Health and Human Services
11 under—

12 “(1) part C of title XI of the Social Security
13 Act (42 U.S.C. 1320d et seq.); or

14 “(2) section 264(e) of the Health Insurance
15 Portability and Accountability Act of 1996 (Public
16 Law 104–191; 110 Stat. 2033).

17 “(e) COLLECTION OF GENETIC INFORMATION.—

18 “(1) LIMITATION ON REQUESTING OR REQUIR-
19 ING GENETIC INFORMATION.—Except as provided in
20 paragraph (2), a health insurance issuer offering
21 health insurance coverage in the individual market
22 shall not request or require genetic information con-
23 cerning an individual or a family member of the in-
24 dividual (including information about a request for
25 or receipt of genetic services).

1 “(2) INFORMATION NEEDED FOR TREATMENT,
 2 PAYMENT, AND HEALTH CARE OPERATIONS.—Not-
 3 withstanding paragraph (1), a health insurance
 4 issuer offering health insurance coverage in the indi-
 5 vidual market that provides health care items and
 6 services to an individual may request genetic infor-
 7 mation concerning such individual or dependent for
 8 purposes of treatment, payment, or health care oper-
 9 ations in accordance with the standards for pro-
 10 tected health information described in subsection (d)
 11 to the extent that the use of such information is oth-
 12 erwise consistent with this section.

13 “(3) FAILURE TO PROVIDE NECESSARY INFOR-
 14 MATION.—If an individual or dependent refuses to
 15 provide the information requested under paragraph
 16 (2), and such information is for treatment, payment,
 17 or health care operations relating to the individual,
 18 the health insurance issuer requesting such informa-
 19 tion shall not be required to provide coverage for the
 20 items, services, or treatments with respect to which
 21 the requested information relates.”.

22 (c) REGULATIONS AND EFFECTIVE DATE.—

23 (1) REGULATIONS.—Not later than 1 year after
 24 the date of enactment of this title, the Secretary of
 25 Labor and the Secretary of Health and Human

1 Services (as the case may be) shall issue final regula-
 2 tions in an accessible format to carry out the
 3 amendments made by this section.

4 (2) EFFECTIVE DATE.—The amendments made
 5 by this section shall apply—

6 (A) with respect to group health plans, and
 7 health insurance coverage offered in connection
 8 with group health plans, for plan years begin-
 9 ning after the date that is 18 months after the
 10 date of enactment of this title; and

11 (B) with respect to health insurance cov-
 12 erage offered, sold, issued, renewed, in effect, or
 13 operated in the individual market after the date
 14 that is 18 months after the date of enactment
 15 of this title.

16 **SEC. 103. AMENDMENTS TO THE INTERNAL REVENUE CODE**
 17 **OF 1986.**

18 (a) PROHIBITION OF HEALTH DISCRIMINATION ON
 19 THE BASIS OF GENETIC INFORMATION OR GENETIC
 20 SERVICES.—

21 (1) NO ENROLLMENT RESTRICTION FOR GE-
 22 NETIC SERVICES.—Section 9802(a)(1)(F) of the In-
 23 ternal Revenue Code of 1986 is amended by insert-
 24 ing before the period the following: “(including in-

1 formation about a request for or receipt of genetic
2 services)”.
3

4 ~~(2) NO DISCRIMINATION IN GROUP PREMIUMS~~
5 ~~BASED ON GENETIC INFORMATION.~~—Section
6 9802(b) of the Internal Revenue Code of 1986 is
7 amended by adding at the end the following:

8 ~~“(3) NO DISCRIMINATION IN GROUP PREMIUMS~~
9 ~~BASED ON GENETIC INFORMATION.~~—For purposes
10 of this section, a group health plan shall not adjust
11 premium or contribution amounts for a group on the
12 basis of genetic information concerning an individual
13 in the group or a family member of the individual
14 (including information about a request for or receipt
15 of genetic services).”.

16 ~~(b) LIMITATIONS ON GENETIC TESTING AND THE~~
17 ~~COLLECTION OF GENETIC INFORMATION.~~—Section 9802
18 of the Internal Revenue Code of 1986 is amended by add-
19 ing at the end the following:

20 ~~“(d) GENETIC TESTING AND GENETIC SERVICES.—~~

21 ~~“(1) LIMITATION ON REQUESTING OR REQUIR-~~
22 ~~ING GENETIC TESTING.~~—A group health plan shall
23 not request or require an individual or a family
24 member of such individual to undergo a genetic test.

25 ~~“(2) RULE OF CONSTRUCTION.~~—Nothing in
this part shall be construed to limit the authority of

1 a health care professional, who is providing health
 2 care services with respect to an individual or who is
 3 acting on behalf of a group health plan, to request
 4 that such individual or a family member of such in-
 5 dividual undergo a genetic test. Such a health care
 6 professional shall not require that such individual or
 7 family member undergo a genetic test.

8 “(e) COMPLIANCE WITH CERTAIN CONFIDENTIALITY
 9 STANDARDS WITH RESPECT TO GENETIC INFORMA-
 10 TION.—With respect to the use or disclosure of genetic
 11 information by a group health plan, such information shall
 12 be deemed to be protected health information for purposes
 13 of, and shall be subject to, the standards promulgated by
 14 the Secretary of Health and Human Services under—

15 “(1) part C of title XI of the Social Security
 16 Act (42 U.S.C. 1320d et seq.); or

17 “(2) section 264(e) of the Health Insurance
 18 Portability and Accountability Act of 1996 (Public
 19 Law 104–191; 110 Stat. 2033).

20 “(f) COLLECTION OF GENETIC INFORMATION.—

21 “(1) LIMITATION ON REQUESTING OR REQUIR-
 22 ING GENETIC INFORMATION.—Except as provided in
 23 paragraph (2), a group health plan shall not request
 24 or require genetic information concerning an indi-
 25 vidual or a family member of the individual (includ-

1 ing information about a request for or receipt of ge-
2 netic services).

3 “(2) INFORMATION NEEDED FOR TREATMENT,
4 PAYMENT, AND HEALTH CARE OPERATIONS.—Not-
5 withstanding paragraph (1), a group health plan
6 that provides health care items and services to an in-
7 dividual may request genetic information concerning
8 such individual or dependent for purposes of treat-
9 ment, payment, or health care operations in accord-
10 ance with the standards for protected health infor-
11 mation described in subsection (c) to the extent that
12 the use of such information is otherwise consistent
13 with this section.

14 “(3) FAILURE TO PROVIDE NECESSARY INFOR-
15 MATION.—If an individual or dependent refuses to
16 provide the information requested under paragraph
17 (2), and such information is for treatment, payment,
18 or health care operations relating to the individual,
19 the group health plan requesting such information
20 shall not be required to provide coverage for the
21 items, services, or treatments with respect to which
22 the requested information relates.”.

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.—

11 “(A) IN GENERAL.—Except as provided in
12 subparagraph (B), the term ‘genetic informa-
13 tion’ means information—

14 “(i) concerning—

15 “(I) the genetic tests of an indi-
16 vidual;

17 “(II) the genetic tests of family
18 members of the individual; or

19 “(III) the occurrence of a disease
20 or disorder in family members of the
21 individual; and

22 “(ii) that is used to predict risk of
23 disease in asymptomatic or undiagnosed
24 individuals.

1 “(B) EXCEPTIONS.—The term ‘genetic in-
2 formation’ shall not include—

3 “(i) information about the sex or age
4 of the individual;

5 “(ii) information derived from clinical
6 and laboratory tests, such as the chemical,
7 blood, or urine analyses of the individual
8 including cholesterol tests, used to deter-
9 mine health status or detect illness or diag-
10 nose disease; and

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

13 “(8) GENETIC SERVICES.—The term ‘genetic
14 services’ means health services provided for genetic
15 education and counseling.

16 “(9) GENETIC TEST.—The term ‘genetic test’
17 means the analysis of human DNA, RNA, chro-
18 mosomes, proteins, and metabolites, that detect
19 genotypes, mutations, or chromosomal changes.
20 Such term does not include information described in
21 paragraph (7)(B).”.

22 (d) REGULATIONS AND EFFECTIVE DATE.—

23 (1) REGULATIONS.—Not later than 1 year after
24 the date of enactment of this title, the Secretary of
25 the Treasury shall issue final regulations in an ac-

1 ecessible format to carry out the amendments made
2 by this section.

3 (2) ~~EFFECTIVE DATE.~~—The amendments made
4 by this section shall apply with respect to group
5 health plans for plan years beginning after the date
6 that is 18 months after the date of enactment of
7 this title.

8 **SEC. 104. ASSURING COORDINATION.**

9 The Secretary of the Treasury, the Secretary of
10 Health and Human Services, and the Secretary of Labor
11 shall ensure, through the execution of an interagency
12 memorandum of understanding among such Secretaries,
13 that—

14 (1) regulations, rulings, and interpretations
15 issued by such Secretaries relating to the same mat-
16 ter over which two or more such Secretaries have re-
17 sponsibility under this title (and the amendments
18 made by this title) are administered so as to have
19 the same effect at all times; and

20 (2) coordination of policies relating to enforcing
21 the same requirements through such Secretaries in
22 order to have a coordinated enforcement strategy
23 that avoids duplication of enforcement efforts and
24 assigns priorities in enforcement.

1 **TITLE II—PROHIBITING EM-**
2 **PLOYMENT DISCRIMINATION**
3 **ON THE BASIS OF GENETIC**
4 **INFORMATION**

5 **SEC. 201. DEFINITIONS.**

6 In this title:

7 (1) **COMMISSION.**—The term “Commission”
8 means the Equal Employment Opportunity Commis-
9 sion as created by section 705 of the Civil Rights
10 Act of 1964 (42 U.S.C. 2000e-4).

11 (2) **EMPLOYEE; EMPLOYER; EMPLOYMENT**
12 **AGENCY; LABOR ORGANIZATION; AND MEMBER.**—

13 The terms—

14 (A) “employee”, “employer”, “employment
15 agency”, and “labor organization” have the
16 meanings given such terms in section 701 of
17 the Civil Rights Act of 1964 (42 U.S.C. 2000e);
18 and

19 (B) “employee” and “member”, as used
20 with respect to a labor organization, include an
21 applicant for employment and an applicant for
22 membership in a labor organization, respec-
23 tively.

24 (3) **FAMILY MEMBER.**—The term “family mem-
25 ber” means with respect to an individual—

1 (A) the spouse of the individual;

2 (B) a dependent child of the individual, in-
3 cluding a child who is born to or placed for
4 adoption with the individual; and

5 (C) all other individuals related by blood to
6 the individual or the spouse or child described
7 in subparagraph (A) or (B).

8 (4) GENETIC INFORMATION.—

9 (A) IN GENERAL.—Except as provided in
10 subparagraph (B), the term “genetic informa-
11 tion” means information—

12 (i) concerning—

13 (I) the genetic tests of an indi-
14 vidual;

15 (II) the genetic tests of family
16 members of the individual; or

17 (III) the occurrence of a disease
18 or disorder in family members of the
19 individual; and

20 (ii) that is used to predict risk of dis-
21 ease in asymptomatic or undiagnosed indi-
22 viduals.

23 (B) EXCEPTIONS.—The term “genetic in-
24 formation” shall not include—

1 (i) information about the sex or age of
2 the individual;

3 (ii) information derived from clinical
4 and laboratory tests, such as the chemical,
5 blood, or urine analyses of the individual
6 including cholesterol tests, used to deter-
7 mine health status or detect illness or diag-
8 nose disease; and

9 (iii) information about physical exams
10 of the individual.

11 (5) GENETIC MONITORING.—The term “genetic
12 monitoring” means the periodic examination of em-
13 ployees to evaluate acquired modifications to their
14 genetic material, such as chromosomal damage or
15 evidence of increased occurrence of mutations, that
16 may have developed in the course of employment due
17 to exposure to toxic substances in the workplace, in
18 order to identify, evaluate, and respond to the ef-
19 fects of or control adverse environmental exposures
20 in the workplace.

21 (6) GENETIC SERVICES.—The term “genetic
22 services” means health services provided for genetic
23 education and counseling.

24 (7) GENETIC TEST.—The term “genetic test”
25 means the analysis of human DNA, RNA, chro-

1 mosomes, proteins, and metabolites, that detect
2 genotypes, mutations, or chromosomal changes.
3 Such term does not include information described in
4 paragraph (4)(B).

5 **SEC. 202. EMPLOYER PRACTICES.**

6 (a) **USE OF GENETIC INFORMATION.**—It shall be an
7 unlawful employment practice for an employer—

8 (1) to fail or refuse to hire or to discharge any
9 individual, or otherwise to discriminate against any
10 individual with respect to the compensation, terms,
11 conditions, or privileges of employment of the indi-
12 vidual, because of genetic information with respect
13 to the individual (or information about a request for
14 or the receipt of genetic services by such individual
15 or family member of such individual); or

16 (2) to limit, segregate, or classify the employees
17 of the employer in any way that would deprive or
18 tend to deprive any individual of employment oppor-
19 tunities or otherwise adversely affect the status of
20 the individual as an employee, because of genetic in-
21 formation with respect to the individual (or informa-
22 tion about a request for or the receipt of genetic
23 services by such individual or family member of such
24 individual).

1 (b) **LIMITATION ON COLLECTION OF GENETIC IN-**
2 **FORMATION.**—It shall be an unlawful employment practice
3 for an employer to intentionally request, require, or pur-
4 chase genetic information with respect to an employee or
5 a family member of the employee (or information about
6 a request for the receipt of genetic services by such em-
7 ployee or a family of such employee) except—

8 (1) where the information involved is to be used
9 for genetic monitoring of the biological effects of
10 toxic substances in the workplace, but only if—

11 (A) the employer provides written notice of
12 the genetic monitoring to the employee;

13 (B)(i) the employee provides prior, know-
14 ing, voluntary, and written authorization; or

15 (ii) the genetic monitoring is required by
16 Federal, State, or local law;

17 (C) the employee is informed of individual
18 monitoring results;

19 (D) the monitoring conforms to any Fed-
20 eral or State genetic monitoring regulations, in-
21 cluding any such regulations that may be pro-
22 mulgated by the Secretary of Labor pursuant to
23 the Occupational Safety and Health Act of
24 1970 (29 U.S.C. 651 et seq.) or the Federal

1 Mine Safety and Health Act of 1977 (30
2 U.S.C. 801 et seq.); and

3 ~~(E) the employer, excluding any licensed or~~
4 ~~certified health care professional that is in-~~
5 ~~involved in the genetic monitoring program, re-~~
6 ~~ceives the results of the monitoring only in ag-~~
7 ~~gregate terms that do not disclose the identity~~
8 ~~of specific employees;~~

9 ~~(2) where—~~

10 ~~(A) health or genetic services are offered~~
11 ~~by the employer;~~

12 ~~(B) the employee provides prior, knowing,~~
13 ~~voluntary, and written authorization; and~~

14 ~~(C) only the employee (or family member~~
15 ~~if the family member is receiving genetic serv-~~
16 ~~ices) and the licensed or certified health care~~
17 ~~professionals involved in providing such services~~
18 ~~receive individually identifiable information con-~~
19 ~~cerning the results of such services; or~~

20 ~~(3) where the request or requirement is nec-~~
21 ~~essary to comply with Federal, State, or local law.~~

22 ~~(c) LIMITATION.—In the case of genetic information~~
23 ~~to which paragraph (1), (2), or (3) of subsection (b) ap-~~
24 ~~plies, such information may not be used in violation of~~
25 ~~paragraph (1) or (2) of subsection (a).~~

1 (d) EXCEPTION.—

2 (1) IN GENERAL.—An employer shall not be
3 considered to engage in an employment practice that
4 is unlawful under this title because of its disparate
5 impact, on the basis that the employer applies a
6 qualification standard, test, or other selection cri-
7 terion that screens out or tends to screen out, or
8 otherwise denies a job benefit to, an individual, if
9 the standard, test, or other selection criterion is
10 shown to be job-related with respect to the employ-
11 ment position involved and consistent with business
12 necessity.

13 (2) QUALIFICATION STANDARD.—In this sub-
14 section, the term “qualification standard” may in-
15 clude a requirement that an individual shall not pose
16 a direct threat to the health or safety of other indi-
17 viduals in the workplace.

18 (e) RULE OF CONSTRUCTION RELATING TO GROUP
19 HEALTH PLANS.—Nothing in this section shall be con-
20 strued to prohibit a group health plan (as such term is
21 defined in section 733(a) of the Employee Retirement In-
22 come Security Act of 1974 (29 U.S.C. 1191b(a))), or a
23 health insurance issuer offering group health insurance
24 coverage in connection with a group health plan, from
25 making a request described in subsection (b) if such re-

1 quest is consistent with the provisions of part 7 of subtitle
2 B of title I of the Employee Retirement Income Security
3 Act of 1974 (29 U.S.C. 1181 et seq.); title XXVII of the
4 Public Health Service (42 U.S.C. 300gg et seq.); and
5 chapter 100 of the Internal Revenue Code of 1986.

6 **SEC. 203. EMPLOYMENT AGENCY PRACTICES.**

7 (a) USE OF GENETIC INFORMATION.—It shall be an
8 unlawful employment practice for an employment agen-
9 cy—

10 (1) to fail or refuse to refer for employment, or
11 otherwise to discriminate against, any individual be-
12 cause of genetic information with respect to the indi-
13 vidual (or information about a request for or the re-
14 ceipt of genetic services by such individual or family
15 member of such individual); or

16 (2) to limit, segregate, or classify individuals or
17 fail or refuse to refer for employment any individual
18 in any way that would deprive or tend to deprive any
19 individual of employment opportunities, or otherwise
20 adversely affect the status of the individual as an
21 employee, because of genetic information with re-
22 spect to the individual (or information about a re-
23 quest for or the receipt of genetic services by such
24 individual or family member of such individual).

1 (b) LIMITATION ON COLLECTION OF GENETIC IN-
2 FORMATION.—It shall be an unlawful employment practice
3 for an employment agency—

4 (1) to intentionally request, require, or pur-
5 chase genetic information with respect to an em-
6 ployee or family member of the employee (or infor-
7 mation about a request for or the receipt of genetic
8 services by such employee or family member of such
9 employee); except that the provisions of section
10 202(b) shall apply with respect to employment agen-
11 cies and employees (and the family members of the
12 employees) under this paragraph in the same man-
13 ner and to the same extent as such provisions apply
14 to employers and employees (and the family mem-
15 bers of the employees) under section 202(b); or

16 (2) to cause or attempt to cause an employer to
17 discriminate against an individual in violation of this
18 title.

19 (c) LIMITATION AND EXCEPTION.—Subsections (c)
20 and (d) of section 202 shall apply with respect to employ-
21 ment agencies and employees (and the family members of
22 the employees) under this section in the same manner and
23 to the same extent as such provisions apply to employers
24 and employees (and the family members of the employees)
25 under section 202.

1 **SEC. 204. LABOR ORGANIZATION PRACTICES.**

2 (a) **USE OF GENETIC INFORMATION.**—It shall be an
3 unlawful employment practice for a labor organization—

4 (1) to exclude or to expel from the membership
5 of the organization, or otherwise to discriminate
6 against, any individual because of genetic informa-
7 tion with respect to the individual (or information
8 about a request for or the receipt of genetic services
9 by such individual or family member of such indi-
10 vidual); or

11 (2) to limit, segregate, or classify the members
12 of the organization, or fail or refuse to refer for em-
13 ployment any individual, in any way that would de-
14 prive or tend to deprive any individual of employ-
15 ment opportunities, or otherwise adversely affect the
16 status of the individual as an employee, because of
17 genetic information with respect to the individual (or
18 information about a request for or the receipt of ge-
19 netic services by such individual or family member
20 of such individual).

21 (b) **LIMITATION ON COLLECTION OF GENETIC IN-**
22 **FORMATION.**—It shall be an unlawful employment practice
23 for a labor organization—

24 (1) to intentionally request, require, or pur-
25 chase genetic information with respect to an indi-
26 vidual who is a member of a labor organization or

1 a family member of the individual (or information
2 about a request for or the receipt of genetic services
3 by such individual or family member of such indi-
4 vidual) except that the provisions of section 202(b)
5 shall apply with respect to labor organizations and
6 such individuals (and their family members) under
7 this paragraph in the same manner and to the same
8 extent as such provisions apply to employers and
9 employees (and the family members of the employ-
10 ees) under section 202(b); or

11 (2) to cause or attempt to cause an employer to
12 discriminate against an individual in violation of this
13 title.

14 (e) **LIMITATION AND EXCEPTION.**—Subsections (e)
15 and (d) of section 202 shall apply with respect to labor
16 organizations and individuals who are members of labor
17 organizations (and the family members of the individuals)
18 under this section in the same manner and to the same
19 extent as such provisions apply to employers and employ-
20 ees (and the family members of the employees) under sec-
21 tion 202.

22 **SEC. 205. TRAINING PROGRAMS.**

23 (a) **USE OF GENETIC INFORMATION.**—It shall be an
24 unlawful employment practice for any employer, labor or-
25 ganization, or joint labor-management committee control-

1 ling apprenticeship or other training or retraining, includ-
 2 ing on-the-job training programs—

3 (1) to discriminate against any individual be-
 4 cause of genetic information with respect to the indi-
 5 vidual (or information about a request for or the re-
 6 ceipt of genetic services by such individual or a fam-
 7 ily member of such individual) in admission to, or
 8 employment in, any program established to provide
 9 apprenticeship or other training or retraining; or

10 (2) to limit, segregate, or classify the applicants
 11 for or participants in such apprenticeship or other
 12 training or retraining, or fail or refuse to refer for
 13 employment any individual, in any way that would
 14 deprive or tend to deprive any individual of employ-
 15 ment opportunities, or otherwise adversely affect the
 16 status of the individual as an employee, because of
 17 genetic information with respect to the individual (or
 18 information about a request for or receipt of genetic
 19 services by such individual or family member of such
 20 individual).

21 (b) **LIMITATION ON COLLECTION OF GENETIC IN-**
 22 **FORMATION.**—It shall be an unlawful employment practice
 23 for an employer, labor organization, or joint labor-man-
 24 agement committee described in subsection (a)—

1 (1) to intentionally request, require, or pur-
2 chase genetic information with respect to an indi-
3 vidual who is an applicant for or a participant in
4 such apprenticeship or other training or retraining
5 (or information about a request for or the receipt of
6 genetic services by such individual or family member
7 of such individual) except that the provisions of sec-
8 tion 202(b) shall apply with respect to such employ-
9 ers, labor organizations, and joint labor-management
10 committees and to such individuals (and their family
11 members) under this paragraph in the same manner
12 and to the same extent as such provisions apply to
13 employers and employees (and their family mem-
14 bers) under section 202(b); or

15 (2) to cause or attempt to cause an employer to
16 discriminate against an applicant for or a partici-
17 pant in such apprenticeship or other training or re-
18 training in violation of this title.

19 (c) LIMITATION AND EXCEPTION.—Subsections (c)
20 and (d) of section 202 shall apply with respect to employ-
21 ers, labor organizations, and joint labor-management com-
22 mittees described in subsection (a) and to individuals who
23 are applicants for or participants in apprenticeship or
24 other training or retraining (and the family members of
25 the individuals) under this section in the same manner and

1 to the same extent as the provisions apply to employers
 2 and to employees (and the family members of the employ-
 3 ees) under section 202.

4 **SEC. 206. CONFIDENTIALITY OF GENETIC INFORMATION.**

5 (a) TREATMENT OF INFORMATION AS PART OF CON-
 6 FIDENTIAL MEDICAL RECORD.—

7 (1) IN GENERAL.—If an employer, employment
 8 agency, labor organization, or joint labor-manage-
 9 ment committee possesses genetic information about
 10 an employee or member (or information about a re-
 11 quest for or receipt of genetic services by such em-
 12 ployee or member or family member of such em-
 13 ployee or member), such information shall be treated
 14 and maintained as part of the employee's or mem-
 15 ber's confidential medical records.

16 (2) LIMITATION ON DISCLOSURE.—An em-
 17 ployer, employment agency, labor organization, or
 18 joint labor-management committee shall not disclose
 19 genetic information concerning an employee or mem-
 20 ber (or information about a request for or receipt of
 21 genetic services by such employee or member or fam-
 22 ily member of such employee or member) except—

23 (A) to the employee (or family member if
 24 the family member is receiving the genetic serv-

1 ices) or member at the request of the employee
2 or member;

3 (B) to an occupational or other health re-
4 searcher if the research is conducted in compli-
5 ance with the regulations and protections pro-
6 vided for under part 46 of title 45, Code of
7 Federal Regulations (or any corresponding
8 similar regulation or rule);

9 (C) under legal compulsion of a Federal or
10 State court order, except that if the court order
11 was secured without the knowledge of the indi-
12 vidual to whom the information refers, the em-
13 ployer shall provide the individual with ade-
14 quate notice to challenge the court order;

15 (D) to government officials who are inves-
16 tigating compliance with this title if the infor-
17 mation is relevant to the investigation;

18 (E) to the extent that such disclosure is
19 necessary to comply with Federal, State, or
20 local law; or

21 (F) as otherwise provided for in this title.

22 (b) **RULE OF CONSTRUCTION RELATING TO GROUP**
23 **HEALTH PLANS.**—Nothing in this section shall be con-
24 strued to prohibit a group health plan (as such term is
25 defined in section 733(a) of the Employee Retirement In-

1 come Security Act of 1974 (29 U.S.C. 1191b(a))), or a
2 health insurance issuer offering group health insurance
3 coverage in connection with a group health plan, from
4 using or disclosing information described in subsection (a)
5 if such use of disclosure is consistent with the provisions
6 of part 7 of subtitle B of title I of the Employee Retirement
7 Income Security Act of 1974 (29 U.S.C. 1181 et
8 seq.); title XXVII of the Public Health Service (42 U.S.C.
9 300gg et seq.); and chapter 100 of the Internal Revenue
10 Code of 1986.

11 **SEC. 207. ENFORCEMENT.**

12 The powers, remedies, and procedures set forth in
13 sections 705, 706, 707, 709, and 710 of the Civil Rights
14 Act of 1964 (42 U.S.C. 2000e-4, 2000e-5, 2000e-6,
15 2000e-8, and 2000e-9) shall be the powers, remedies, and
16 procedures that this title provides to the Commission, to
17 the Attorney General, or to any person alleging an unlaw-
18 ful employment practice in violation of section 202 (other
19 than subsection (e) of such section), 203, 204, 205, or
20 206(a) or the regulations promulgated under section 210,
21 concerning employment.

22 **SEC. 208. AMENDMENT TO THE REVISED STATUTES.**

23 (a) **RIGHT OF RECOVERY.**—Section 1977A(a) of the
24 Revised Statutes (42 U.S.C. 1981a(a)) is amended by
25 adding at the end the following:

1 “(4) GENETIC INFORMATION.—In an action
2 brought by a complaining party under the powers,
3 remedies, and procedures set forth in section 706 of
4 the Civil Rights Act of 1964 (42 U.S.C. 2000e–5),
5 as authorized under section 207 of the Genetic In-
6 formation Nondiscrimination Act of 2003, against a
7 respondent who is engaging (or has engaged) in an
8 intentional unlawful employment practice prohibited
9 by section 202 (other than subsection (c) of such
10 section), 203, 204, 205 or 206(a) of such Genetic
11 Information Nondiscrimination Act of 2003 against
12 an individual (other than an action involving an em-
13 ployment practice that is allegedly unlawful because
14 of its disparate impact), the complaining party may
15 recover compensatory and punitive damages as per-
16 mitted under subsection (b), in addition to any relief
17 otherwise provided for under section 706(g) of the
18 Civil Rights Act of 1964 (42 U.S.C. 2000e–5(g)),
19 from the respondent.”.

20 (b) CONFORMING AMENDMENTS.—Section 1977A(d)
21 of the Revised Statutes (42 U.S.C. 1981a(d)) is amend-
22 ed—

23 (1) in paragraph (1)—

24 (A) in subparagraph (A), by striking “or”
25 at the end;

1 (B) in subparagraph (B), by striking the
2 period and inserting “; or”; and

3 (C) by adding at the end the following:

4 “(C) in the case of a person seeking to
5 bring an action under subsection (a)(4) ,the
6 Equal Employment Opportunity Commission,
7 the Attorney General, or a person who may
8 bring an action or proceeding under title II of
9 the Genetic Information Nondiscrimination Act
10 of 2003.”; and

11 (2) in paragraph (2), by striking “or the dis-
12 crimination or the violation described in paragraph
13 (2),” and inserting “the discrimination or the viola-
14 tion described in paragraph (2), or the intentional
15 unlawful employment practice described in para-
16 graph (4),”.

17 **SEC. 209. CONSTRUCTION.**

18 Nothing in this title shall be construed to—

19 (1) limit the rights or protections of an indi-
20 vidual under the Americans with Disabilities Act of
21 1990 (42 U.S.C. 12101 et seq.), including coverage
22 afforded to individuals under section 102 of such
23 Act (42 U.S.C. 12112), or under the Rehabilitation
24 Act of 1973 (29 U.S.C. 701 et seq.), except that an
25 individual may not bring an action against an em-

1 ployer, employment agency, labor organization, or
2 joint labor-management committee pursuant to this
3 title and also pursuant to the Americans with Dis-
4 abilities Act of 1990 or the Rehabilitation Act of
5 1973, if the actions are predicated on the same facts
6 or a common occurrence;

7 (2) limit the rights or protections of an indi-
8 vidual to bring an action under this title against an
9 employer, employment agency, labor organization, or
10 joint labor-management committee for a violation of
11 this title, except that an individual may not bring an
12 action against such an employer, employment agen-
13 cy, labor organization, or joint labor-management
14 committee, with respect to a group health plan or a
15 health insurance issuer offering health insurance
16 coverage in connection with a group health plan;
17 under this title if the action is based on a violation
18 of a provision of the amendments made by title I;

19 (3) limit the rights or protections of an indi-
20 vidual under any other Federal or State statute that
21 provides equal or greater protection to an individual
22 than the rights or protections provided for under
23 this title;

24 (4) apply to the Armed Forces Repository of
25 Specimen Samples for the Identification of Remains;

1 (5) limit the authority of a Federal department
2 or agency to conduct or sponsor occupational or
3 other health research that is conducted in compli-
4 ance with the regulations contained in part 46 of
5 title 45, Code of Federal Regulations (or any cor-
6 responding or similar regulation or rule); and

7 (6) limit the statutory or regulatory authority
8 of the Occupational Safety and Health Administra-
9 tion or the Mine Safety and Health Administration
10 to promulgate or enforce workplace safety and
11 health laws and regulations.

12 **SEC. 210. REGULATIONS.**

13 Not later than 1 year after the date of enactment
14 of this title, the Commission shall issue final regulations
15 in an accessible format to carry out this title.

16 **SEC. 211. SEVERABILITY.**

17 If any provision of this title, an amendment made by
18 this title, or the application of such provision or amend-
19 ment to any person or circumstance is held to be unconsti-
20 tutional, the remainder of this title, the amendments made
21 by this title, and the application of such provisions to any
22 person or circumstance shall not be affected thereby.

23 **SEC. 212. AUTHORIZATION OF APPROPRIATIONS.**

24 There are authorized to be appropriated such sums
25 as may be necessary to carry out this title.

1 **SEC. 213. EFFECTIVE DATE.**

2 (a) **IN GENERAL.**—This title takes effect on the date
3 that is 18 months after the date of enactment of this Act.

4 (b) **ENFORCEMENT.**—Notwithstanding subsection
5 (a), no enforcement action shall be commenced under sec-
6 tion 207 until the date on which the Commission issues
7 final regulations under section 210.

8 **SECTION 1. SHORT TITLE.**

9 *This Act may be cited as the “Genetic Information*
10 *Nondiscrimination Act of 2003”.*

11 **TITLE I—GENETIC NON-**
12 **DISCRIMINATION IN HEALTH**
13 **INSURANCE**

14 **SEC. 101. AMENDMENTS TO EMPLOYEE RETIREMENT IN-**
15 **COME SECURITY ACT OF 1974.**

16 (a) **PROHIBITION OF HEALTH DISCRIMINATION ON**
17 **THE BASIS OF GENETIC INFORMATION OR GENETIC SERV-**
18 **ICES.**—

19 (1) **NO ENROLLMENT RESTRICTION FOR GENETIC**
20 **SERVICES.**—Section 702(a)(1)(F) of the *Employee Re-*
21 *tirement Income Security Act of 1974 (29 U.S.C.*
22 *1182(a)(1)(F))* is amended by inserting before the pe-
23 *riod the following: “(including information about a*
24 *request for or receipt of genetic services by an indi-*
25 *vidual or family member of such individual)”.*

1 (2) *NO DISCRIMINATION IN GROUP PREMIUMS*
 2 *BASED ON GENETIC INFORMATION.*—Section 702(b) of
 3 *the Employee Retirement Income Security Act of*
 4 *1974 (29 U.S.C. 1182(b)) is amended—*

5 (A) *in paragraph (2)(A), by inserting before*
 6 *the semicolon the following: “except as provided*
 7 *in paragraph (3)”;* and

8 (B) *by adding at the end the following:*

9 “(3) *NO DISCRIMINATION IN GROUP PREMIUMS*
 10 *BASED ON GENETIC INFORMATION.*—For purposes of
 11 *this section, a group health plan, or a health insur-*
 12 *ance issuer offering group health insurance coverage*
 13 *in connection with a group health plan, shall not ad-*
 14 *just premium or contribution amounts for a group on*
 15 *the basis of genetic information concerning an indi-*
 16 *vidual in the group or a family member of the indi-*
 17 *vidual (including information about a request for or*
 18 *receipt of genetic services by an individual or family*
 19 *member of such individual).”.*

20 (b) *LIMITATIONS ON GENETIC TESTING.*—Section 702
 21 *of the Employee Retirement Income Security Act of 1974*
 22 *(29 U.S.C. 1182) is amended by adding at the end the fol-*
 23 *lowing:*

24 “(c) *GENETIC TESTING.*—

1 “(1) *LIMITATION ON REQUESTING OR REQUIRING*
2 *GENETIC TESTING.*—A group health plan, or a health
3 insurance issuer offering health insurance coverage in
4 connection with a group health plan, shall not request
5 or require an individual or a family member of such
6 individual to undergo a genetic test.

7 “(2) *RULE OF CONSTRUCTION.*—Nothing in this
8 part shall be construed to—

9 “(A) limit the authority of a health care
10 professional who is providing health care services
11 with respect to an individual to request that
12 such individual or a family member of such in-
13 dividual undergo a genetic test;

14 “(B) limit the authority of a health care
15 professional who is employed by or affiliated
16 with a group health plan or a health insurance
17 issuer and who is providing health care services
18 to an individual as part of a bona fide wellness
19 program to notify such individual of the avail-
20 ability of a genetic test or to provide information
21 to such individual regarding such genetic test; or

22 “(C) authorize or permit a health care pro-
23 fessional to require that an individual undergo a
24 genetic test.

1 “(d) *APPLICATION TO ALL PLANS.*—The provisions of
 2 subsections (a)(1)(F), (b)(3), and (c) shall apply to group
 3 health plans and health insurance issuers without regard
 4 to section 732(a).”.

5 (c) *REMEDIES AND ENFORCEMENT.*—Section 502 of
 6 the Employee Retirement Income Security Act of 1974 (29
 7 U.S.C. 1132) is amended by adding at the end the following:

8 “(n) *ENFORCEMENT OF GENETIC NONDISCRIMINATION*
 9 *REQUIREMENTS.*—

10 “(1) *INJUNCTIVE RELIEF FOR IRREPARABLE*
 11 *HARM.*—With respect to any violation of subsection
 12 (a)(1)(F), (b)(3), or (c) of section 702, a participant
 13 or beneficiary may seek relief under subsection
 14 502(a)(1)(B) prior to the exhaustion of available ad-
 15 ministrative remedies under section 503 if it is dem-
 16 onstrated to the court, by a preponderance of the evi-
 17 dence, that the exhaustion of such remedies would
 18 cause irreparable harm to the health of the partici-
 19 pant or beneficiary. Any determinations that already
 20 have been made under section 503 in such case, or
 21 that are made in such case while an action under this
 22 paragraph is pending, shall be given due consider-
 23 ation by the court in any action under this subsection
 24 in such case.

1 “(2) *EQUITABLE RELIEF FOR GENETIC NON-*
2 *DISCRIMINATION.*—

3 “(A) *REINSTATEMENT OF BENEFITS WHERE*
4 *EQUITABLE RELIEF HAS BEEN AWARDED.*—*The*
5 *recovery of benefits by a participant or bene-*
6 *ficiary under a civil action under this section*
7 *may include an administrative penalty under*
8 *subparagraph (B) and the retroactive reinstatement*
9 *of coverage under the plan involved to the*
10 *date on which the participant or beneficiary was*
11 *denied eligibility for coverage if—*

12 “(i) *the civil action was commenced*
13 *under subsection (a)(1)(B); and*

14 “(ii) *the denial of coverage on which*
15 *such civil action was based constitutes a*
16 *violation of subsection (a)(1)(F), (b)(3), or*
17 *(c) of section 702.*

18 “(B) *ADMINISTRATIVE PENALTY.*—

19 “(i) *IN GENERAL.*—*An administrator*
20 *who fails to comply with the requirements*
21 *of subsection (a)(1)(F), (b)(3), or (c) of sec-*
22 *tion 702 with respect to a participant or*
23 *beneficiary may, in an action commenced*
24 *under subsection (a)(1)(B), be personally*
25 *liable in the discretion of the court, for a*

1 *penalty in the amount not more than \$100*
2 *for each day in the noncompliance period.*

3 *“(ii) NONCOMPLIANCE PERIOD.—For*
4 *purposes of clause (i), the term ‘noncompli-*
5 *ance period’ means the period—*

6 *“(I) beginning on the date that a*
7 *failure described in clause (i) occurs;*
8 *and*

9 *“(II) ending on the date that such*
10 *failure is corrected.*

11 *“(iii) PAYMENT TO PARTICIPANT OR*
12 *BENEFICIARY.—A penalty collected under*
13 *this subparagraph shall be paid to the par-*
14 *ticipant or beneficiary involved.*

15 *“(3) SECRETARIAL ENFORCEMENT AUTHORITY.—*

16 *“(A) GENERAL RULE.—The Secretary has*
17 *the authority to impose a penalty on any failure*
18 *of a group health plan to meet the requirements*
19 *of subsection (a)(1)(F), (b)(3), or (c) of section*
20 *702.*

21 *“(B) AMOUNT.—*

22 *“(i) IN GENERAL.—The amount of the*
23 *penalty imposed by subparagraph (A) shall*
24 *be \$100 for each day in the noncompliance*

1 *period with respect to each individual to*
2 *whom such failure relates.*

3 “(ii) *NONCOMPLIANCE PERIOD.*—*For*
4 *purposes of this paragraph, the term ‘non-*
5 *compliance period’ means, with respect to*
6 *any failure, the period—*

7 *“(I) beginning on the date such*
8 *failure first occurs; and*

9 *“(II) ending on the date such fail-*
10 *ure is corrected.*

11 “(C) *MINIMUM PENALTIES WHERE FAILURE*
12 *DISCOVERED.*—*Notwithstanding clauses (i) and*
13 *(ii) of subparagraph (D):*

14 “(i) *IN GENERAL.*—*In the case of 1 or*
15 *more failures with respect to an indi-*
16 *vidual—*

17 *“(I) which are not corrected before*
18 *the date on which the plan receives a*
19 *notice from the Secretary of such viola-*
20 *tion; and*

21 *“(II) which occurred or continued*
22 *during the period involved;*

23 *the amount of penalty imposed by subpara-*
24 *graph (A) by reason of such failures with*

1 *respect to such individual shall not be less*
2 *than \$2,500.*

3 “(i) *HIGHER MINIMUM PENALTY*
4 *WHERE VIOLATIONS ARE MORE THAN DE*
5 *MINIMIS.—To the extent violations for*
6 *which any person is liable under this para-*
7 *graph for any year are more than de mini-*
8 *mis, clause (i) shall be applied by sub-*
9 *stituting ‘\$15,000’ for ‘\$2,500’ with respect*
10 *to such person.*

11 “(D) *LIMITATIONS.—*

12 “(i) *PENALTY NOT TO APPLY WHERE*
13 *FAILURE NOT DISCOVERED EXERCISING*
14 *REASONABLE DILIGENCE.—No penalty shall*
15 *be imposed by subparagraph (A) on any*
16 *failure during any period for which it is es-*
17 *tablished to the satisfaction of the Secretary*
18 *that the person otherwise liable for such*
19 *penalty did not know, and exercising rea-*
20 *sonable diligence would not have known,*
21 *that such failure existed.*

22 “(i) *PENALTY NOT TO APPLY TO FAIL-*
23 *URES CORRECTED WITHIN CERTAIN PERI-*
24 *ODS.—No penalty shall be imposed by sub-*
25 *paragraph (A) on any failure if—*

1 “(I) such failure was due to rea-
2 sonable cause and not to willful ne-
3 glect; and

4 “(II) such failure is corrected dur-
5 ing the 30-day period beginning on the
6 first date the person otherwise liable
7 for such penalty knew, or exercising
8 reasonable diligence would have known,
9 that such failure existed.

10 “(iii) *OVERALL LIMITATION FOR UNIN-*
11 *TENTIONAL FAILURES.—In the case of fail-*
12 *ures which are due to reasonable cause and*
13 *not to willful neglect, the penalty imposed*
14 *by subparagraph (A) for failures shall not*
15 *exceed the amount equal to the lesser of—*

16 “(I) 10 percent of the aggregate
17 amount paid or incurred by the em-
18 ployer (or predecessor employer) dur-
19 ing the preceding taxable year for
20 group health plans; or

21 “(II) \$500,000.

22 “(E) *WAIVER BY SECRETARY.—In the case*
23 *of a failure which is due to reasonable cause and*
24 *not to willful neglect, the Secretary may waive*
25 *part or all of the penalty imposed by subpara-*

1 *graph (A) to the extent that the payment of such*
2 *penalty would be excessive relative to the failure*
3 *involved.”.*

4 (d) *DEFINITIONS.*—*Section 733(d) of the Employee*
5 *Retirement Income Security Act of 1974 (29 U.S.C.*
6 *1191b(d)) is amended by adding at the end the following:*

7 “(5) *FAMILY MEMBER.*—*The term ‘family mem-*
8 *ber’ means with respect to an individual—*

9 “(A) *the spouse of the individual;*

10 “(B) *a dependent child of the individual,*
11 *including a child who is born to or placed for*
12 *adoption with the individual; and*

13 “(C) *all other individuals related by blood*
14 *to the individual or the spouse or child described*
15 *in subparagraph (A) or (B).*

16 “(6) *GENETIC INFORMATION.*—

17 “(A) *IN GENERAL.*—*Except as provided in*
18 *subparagraph (B), the term ‘genetic information’*
19 *means information about—*

20 “(i) *an individual’s genetic tests;*

21 “(ii) *the genetic tests of family mem-*
22 *bers of the individual; or*

23 “(iii) *the occurrence of a disease or*
24 *disorder in family members of the indi-*
25 *vidual.*

1 “(B) *EXCLUSIONS.*—*The term ‘genetic in-*
2 *formation’ shall not include information about*
3 *the sex or age of an individual.*

4 “(7) *GENETIC TEST.*—

5 “(A) *IN GENERAL.*—*The term ‘genetic test’*
6 *means an analysis of human DNA, RNA, chro-*
7 *mosomes, proteins, or metabolites, that detects*
8 *genotypes, mutations, or chromosomal changes.*

9 “(B) *EXCEPTIONS.*—*The term ‘genetic test’*
10 *does not mean—*

11 “(i) *an analysis of proteins or metabo-*
12 *lites that does not detect genotypes,*
13 *mutations, or chromosomal changes; or*

14 “(ii) *an analysis of proteins or me-*
15 *tabolites that is directly related to a mani-*
16 *fested disease, disorder, or pathological con-*
17 *dition that could reasonably be detected by*
18 *a health care professional with appropriate*
19 *training and expertise in the field of medi-*
20 *cine involved.*

21 “(8) *GENETIC SERVICES.*—*The term ‘genetic*
22 *services’ means—*

23 “(A) *a genetic test;*

1 “(B) genetic counseling (such as obtaining,
2 interpreting, or assessing genetic information);
3 or

4 “(C) genetic education.”.

5 (e) *REGULATIONS AND EFFECTIVE DATE.*—

6 (1) *REGULATIONS.*—Not later than 1 year after
7 the date of enactment of this title, the Secretary of
8 Labor shall issue final regulations in an accessible
9 format to carry out the amendments made by this sec-
10 tion.

11 (2) *EFFECTIVE DATE.*—The amendments made
12 by this section shall apply with respect to group
13 health plans for plan years beginning after the date
14 that is 18 months after the date of enactment of this
15 title.

16 **SEC. 102. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**
17 **ACT.**

18 (a) *AMENDMENTS RELATING TO THE GROUP MAR-*
19 *KET.*—

20 (1) *PROHIBITION OF HEALTH DISCRIMINATION*
21 *ON THE BASIS OF GENETIC INFORMATION OR GENETIC*
22 *SERVICES.*—

23 (A) *NO ENROLLMENT RESTRICTION FOR GE-*
24 *NETIC SERVICES.*—Section 2702(a)(1)(F) of the
25 Public Health Service Act (42 U.S.C. 300gg–

1 1(a)(1)(F)) is amended by inserting before the
2 period the following: “(including information
3 about a request for or receipt of genetic services
4 by an individual or family member of such indi-
5 vidual)”.

6 (B) *NO DISCRIMINATION IN GROUP PRE-*
7 *MIUMS BASED ON GENETIC INFORMATION.*—*Sec-*
8 *tion 2702(b) of the Public Health Service Act (42*
9 *U.S.C. 300gg-1(b)) is amended—*

10 (i) in paragraph (2)(A), by inserting
11 before the semicolon the following: “, except
12 as provided in paragraph (3)”;

13 (ii) by adding at the end the following:

14 “(3) *NO DISCRIMINATION IN GROUP PREMIUMS*
15 *BASED ON GENETIC INFORMATION.*—*For purposes of*
16 *this section, a group health plan, or a health insur-*
17 *ance issuer offering group health insurance coverage*
18 *in connection with a group health plan, shall not ad-*
19 *just premium or contribution amounts for a group on*
20 *the basis of genetic information concerning an indi-*
21 *vidual in the group or a family member of the indi-*
22 *vidual (including information about a request for or*
23 *receipt of genetic services by an individual or family*
24 *member of such individual).”.*

1 (2) *LIMITATIONS ON GENETIC TESTING.*—Section
2 2702 of the Public Health Service Act (42 U.S.C.
3 300gg–1) is amended by adding at the end the fol-
4 lowing:

5 “(c) *GENETIC TESTING.*—

6 “(1) *LIMITATION ON REQUESTING OR REQUIRING*
7 *GENETIC TESTING.*—A group health plan, or a health
8 insurance issuer offering health insurance coverage in
9 connection with a group health plan, shall not request
10 or require an individual or a family member of such
11 individual to undergo a genetic test.

12 “(2) *RULE OF CONSTRUCTION.*—Nothing in this
13 part shall be construed to—

14 “(A) limit the authority of a health care
15 professional who is providing health care services
16 with respect to an individual to request that
17 such individual or a family member of such in-
18 dividual undergo a genetic test;

19 “(B) limit the authority of a health care
20 professional who is employed by or affiliated
21 with a group health plan or a health insurance
22 issuer and who is providing health care services
23 to an individual as part of a bona fide wellness
24 program to notify such individual of the avail-

1 *ability of a genetic test or to provide information*
 2 *to such individual regarding such genetic test; or*
 3 “(C) *authorize or permit a health care pro-*
 4 *fessional to require that an individual undergo a*
 5 *genetic test.*

6 “(d) *APPLICATION TO ALL PLANS.—The provisions of*
 7 *subsections (a)(1)(F), (b)(3), and (c) shall apply to group*
 8 *health plans and health insurance issuers without regard*
 9 *to section 2721(a).”.*

10 (3) *REMEDIES AND ENFORCEMENT.—Section*
 11 *2722(b) of the Public Health Service Act (42 U.S.C.*
 12 *300gg-22)(b)) is amended by adding at the end the*
 13 *following:*

14 “(3) *ENFORCEMENT AUTHORITY RELATING TO*
 15 *GENETIC DISCRIMINATION.—*

16 “(A) *GENERAL RULE.—In the cases de-*
 17 *scribed in paragraph (1), notwithstanding the*
 18 *provisions of paragraph (2)(C), the following*
 19 *provisions shall apply with respect to an action*
 20 *under this subsection by the Secretary with re-*
 21 *spect to any failure of a health insurance issuer*
 22 *in connection with a group health plan, to meet*
 23 *the requirements of subsection (a)(1)(F), (b)(3),*
 24 *or (c) of section 2702.*

25 “(B) *AMOUNT.—*

1 “(i) *IN GENERAL.*—*The amount of the*
 2 *penalty imposed under this paragraph shall*
 3 *be \$100 for each day in the noncompliance*
 4 *period with respect to each individual to*
 5 *whom such failure relates.*

6 “(ii) *NONCOMPLIANCE PERIOD.*—*For*
 7 *purposes of this paragraph, the term ‘non-*
 8 *compliance period’ means, with respect to*
 9 *any failure, the period—*

10 “(I) *beginning on the date such*
 11 *failure first occurs; and*

12 “(II) *ending on the date such fail-*
 13 *ure is corrected.*

14 “(C) *MINIMUM PENALTIES WHERE FAILURE*
 15 *DISCOVERED.*—*Notwithstanding clauses (i) and*
 16 *(ii) of subparagraph (D):*

17 “(i) *IN GENERAL.*—*In the case of 1 or*
 18 *more failures with respect to an indi-*
 19 *vidual—*

20 “(I) *which are not corrected before*
 21 *the date on which the plan receives a*
 22 *notice from the Secretary of such viola-*
 23 *tion; and*

24 “(II) *which occurred or continued*
 25 *during the period involved;*

1 *the amount of penalty imposed by subpara-*
2 *graph (A) by reason of such failures with*
3 *respect to such individual shall not be less*
4 *than \$2,500.*

5 “(i) *HIGHER MINIMUM PENALTY*
6 *WHERE VIOLATIONS ARE MORE THAN DE*
7 *MINIMIS.—To the extent violations for*
8 *which any person is liable under this para-*
9 *graph for any year are more than de mini-*
10 *mis, clause (i) shall be applied by sub-*
11 *stituting ‘\$15,000’ for ‘\$2,500’ with respect*
12 *to such person.*

13 “(D) *LIMITATIONS.—*

14 “(i) *PENALTY NOT TO APPLY WHERE*
15 *FAILURE NOT DISCOVERED EXERCISING*
16 *REASONABLE DILIGENCE.—No penalty shall*
17 *be imposed by subparagraph (A) on any*
18 *failure during any period for which it is es-*
19 *tablished to the satisfaction of the Secretary*
20 *that the person otherwise liable for such*
21 *penalty did not know, and exercising rea-*
22 *sonable diligence would not have known,*
23 *that such failure existed.*

24 “(i) *PENALTY NOT TO APPLY TO FAIL-*
25 *URES CORRECTED WITHIN CERTAIN PERI-*

1 *ODS.—No penalty shall be imposed by sub-*
2 *paragraph (A) on any failure if—*

3 *“(I) such failure was due to rea-*
4 *sonable cause and not to willful ne-*
5 *glect; and*

6 *“(II) such failure is corrected dur-*
7 *ing the 30-day period beginning on the*
8 *first date the person otherwise liable*
9 *for such penalty knew, or exercising*
10 *reasonable diligence would have known,*
11 *that such failure existed.*

12 *“(iii) OVERALL LIMITATION FOR UNIN-*
13 *TENTIONAL FAILURES.—In the case of fail-*
14 *ures which are due to reasonable cause and*
15 *not to willful neglect, the penalty imposed*
16 *by subparagraph (A) for failures shall not*
17 *exceed the amount equal to the lesser of—*

18 *“(I) 10 percent of the aggregate*
19 *amount paid or incurred by the em-*
20 *ployer (or predecessor employer) dur-*
21 *ing the preceding taxable year for*
22 *group health plans; or*

23 *“(II) \$500,000.*

24 *“(E) WAIVER BY SECRETARY.—In the case*
25 *of a failure which is due to reasonable cause and*

1 *not to willful neglect, the Secretary may waive*
2 *part or all of the penalty imposed by subpara-*
3 *graph (A) to the extent that the payment of such*
4 *penalty would be excessive relative to the failure*
5 *involved.”.*

6 (4) *DEFINITIONS.*—*Section 2791(d) of the Public*
7 *Health Service Act (42 U.S.C. 300gg–91(d)) is*
8 *amended by adding at the end the following:*

9 “(15) *FAMILY MEMBER.*—*The term ‘family mem-*
10 *ber’ means with respect to an individual—*

11 “(A) *the spouse of the individual;*

12 “(B) *a dependent child of the individual,*
13 *including a child who is born to or placed for*
14 *adoption with the individual; and*

15 “(C) *all other individuals related by blood*
16 *to the individual or the spouse or child described*
17 *in subparagraph (A) or (B).*

18 “(16) *GENETIC INFORMATION.*—

19 “(A) *IN GENERAL.*—*Except as provided in*
20 *subparagraph (B), the term ‘genetic information’*
21 *means information about—*

22 “(i) *an individual’s genetic tests;*

23 “(ii) *the genetic tests of family mem-*
24 *bers of the individual; or*

1 “(iii) the occurrence of a disease or
2 disorder in family members of the indi-
3 vidual.

4 “(B) EXCLUSIONS.—The term ‘genetic in-
5 formation’ shall not include information about
6 the sex or age of an individual.

7 “(17) GENETIC TEST.—

8 “(A) IN GENERAL.—The term ‘genetic test’
9 means an analysis of human DNA, RNA, chro-
10 mosomes, proteins, or metabolites, that detects
11 genotypes, mutations, or chromosomal changes.

12 “(B) EXCEPTIONS.—The term ‘genetic test’
13 does not mean—

14 “(i) an analysis of proteins or metabo-
15 lites that does not detect genotypes,
16 mutations, or chromosomal changes; or

17 “(ii) an analysis of proteins or me-
18 tabolites that is directly related to a mani-
19 fested disease, disorder, or pathological con-
20 dition that could reasonably be detected by
21 a health care professional with appropriate
22 training and expertise in the field of medi-
23 cine involved.

24 “(18) GENETIC SERVICES.—The term ‘genetic
25 services’ means—

1 “(A) a genetic test;

2 “(B) genetic counseling (such as obtaining,
3 interpreting, or assessing genetic information);

4 or

5 “(C) genetic education.”.

6 (b) *AMENDMENT RELATING TO THE INDIVIDUAL MAR-*
7 *KET.*—

8 (1) *IN GENERAL.*—*The first subpart 3 of part B*
9 *of title XXVII of the Public Health Service Act (42*
10 *U.S.C. 300gg–51 et seq.) (relating to other require-*
11 *ments) is amended—*

12 (A) *by redesignating such subpart as sub-*
13 *part 2; and*

14 (B) *by adding at the end the following:*

15 **“SEC. 2753. PROHIBITION OF HEALTH DISCRIMINATION ON**
16 **THE BASIS OF GENETIC INFORMATION.**

17 “(a) *PROHIBITION ON GENETIC INFORMATION AS A*
18 *CONDITION OF ELIGIBILITY.*—*A health insurance issuer of-*
19 *fering health insurance coverage in the individual market*
20 *may not establish rules for the eligibility (including contin-*
21 *ued eligibility) of any individual to enroll in individual*
22 *health insurance coverage based on genetic information (in-*
23 *cluding information about a request for or receipt of genetic*
24 *services by an individual or family member of such indi-*
25 *vidual).*

1 “(b) *PROHIBITION ON GENETIC INFORMATION IN SET-*
2 *TING PREMIUM RATES.*—*A health insurance issuer offering*
3 *health insurance coverage in the individual market shall*
4 *not adjust premium or contribution amounts for an indi-*
5 *vidual on the basis of genetic information concerning the*
6 *individual or a family member of the individual (including*
7 *information about a request for or receipt of genetic services*
8 *by an individual or family member of such individual).*

9 “(c) *GENETIC TESTING.*—

10 “(1) *LIMITATION ON REQUESTING OR REQUIRING*
11 *GENETIC TESTING.*—*A health insurance issuer offer-*
12 *ing health insurance coverage in the individual mar-*
13 *ket shall not request or require an individual or a*
14 *family member of such individual to undergo a ge-*
15 *netic test.*

16 “(2) *RULE OF CONSTRUCTION.*—*Nothing in this*
17 *part shall be construed to—*

18 “(A) *limit the authority of a health care*
19 *professional who is providing health care services*
20 *with respect to an individual to request that*
21 *such individual or a family member of such in-*
22 *dividual undergo a genetic test;*

23 “(B) *limit the authority of a health care*
24 *professional who is employed by or affiliated*
25 *with a health insurance issuer and who is pro-*

1 *viding health care services to an individual as*
 2 *part of a bona fide wellness program to notify*
 3 *such individual of the availability of a genetic*
 4 *test or to provide information to such individual*
 5 *regarding such genetic test; or*

6 *“(C) authorize or permit a health care pro-*
 7 *fessional to require that an individual undergo a*
 8 *genetic test.”.*

9 *(2) REMEDIES AND ENFORCEMENT.—Section*
 10 *2761(b) of the Public Health Service Act (42 U.S.C.*
 11 *300gg–61)(b)) is amended to read as follows:*

12 *“(b) SECRETARIAL ENFORCEMENT AUTHORITY.—The*
 13 *Secretary shall have the same authority in relation to en-*
 14 *forcement of the provisions of this part with respect to*
 15 *issuers of health insurance coverage in the individual mar-*
 16 *ket in a State as the Secretary has under section 2722(b)(2),*
 17 *and section 2722(b)(3) with respect to violations of genetic*
 18 *nondiscrimination provisions, in relation to the enforce-*
 19 *ment of the provisions of part A with respect to issuers of*
 20 *health insurance coverage in the small group market in the*
 21 *State.”.*

22 *(c) ELIMINATION OF OPTION OF NON-FEDERAL GOV-*
 23 *ERNMENTAL PLANS TO BE EXCEPTED FROM REQUIRE-*
 24 *MENTS CONCERNING GENETIC INFORMATION.—Section*

1 2721(b)(2) of the Public Health Service Act (42 U.S. C.
2 300gg-21(b)(2)) is amended—

3 (1) in subparagraph (A), by striking “If the
4 plan sponsor” and inserting “Except as provided in
5 subparagraph (D), if the plan sponsor”; and

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

7 “(D) *ELECTION NOT APPLICABLE TO RE-*
8 *QUIREMENTS CONCERNING GENETIC INFORMA-*
9 *TION.—The election described in subparagraph*
10 *(A) shall not be available with respect to the pro-*
11 *visions of subsections (a)(1)(F) and (c) of section*
12 *2702 and the provisions of section 2702(b) to the*
13 *extent that such provisions apply to genetic in-*
14 *formation (or information about a request for or*
15 *the receipt of genetic services by an individual or*
16 *a family member of such individual).”.*

17 (d) *REGULATIONS AND EFFECTIVE DATE.—*

18 (1) *REGULATIONS.—Not later than 1 year after*
19 *the date of enactment of this title, the Secretary of*
20 *Labor and the Secretary of Health and Human Serv-*
21 *ices (as the case may be) shall issue final regulations*
22 *in an accessible format to carry out the amendments*
23 *made by this section.*

24 (2) *EFFECTIVE DATE.—The amendments made*
25 *by this section shall apply—*

1 (A) with respect to group health plans, and
2 health insurance coverage offered in connection
3 with group health plans, for plan years begin-
4 ning after the date that is 18 months after the
5 date of enactment of this title; and

6 (B) with respect to health insurance cov-
7 erage offered, sold, issued, renewed, in effect, or
8 operated in the individual market after the date
9 that is 18 months after the date of enactment of
10 this title.

11 **SEC. 103. AMENDMENTS TO THE INTERNAL REVENUE CODE**
12 **OF 1986.**

13 (a) *PROHIBITION OF HEALTH DISCRIMINATION ON*
14 *THE BASIS OF GENETIC INFORMATION OR GENETIC SERV-*
15 *ICES.—*

16 (1) *NO ENROLLMENT RESTRICTION FOR GENETIC*
17 *SERVICES.—Section 9802(a)(1)(F) of the Internal*
18 *Revenue Code of 1986 is amended by inserting before*
19 *the period the following: “(including information*
20 *about a request for or receipt of genetic services by an*
21 *individual or family member of such individual)”.*

22 (2) *NO DISCRIMINATION IN GROUP PREMIUMS*
23 *BASED ON GENETIC INFORMATION.—Section 9802(b)*
24 *of the Internal Revenue Code of 1986 is amended—*

1 (A) in paragraph (2)(A), by inserting before
 2 the semicolon the following: “, except as provided
 3 in paragraph (3)”; and

4 (B) by adding at the end the following:

5 “(3) *NO DISCRIMINATION IN GROUP PREMIUMS*
 6 *BASED ON GENETIC INFORMATION.*—For purposes of
 7 this section, a group health plan shall not adjust pre-
 8 mium or contribution amounts for a group on the
 9 basis of genetic information concerning an individual
 10 in the group or a family member of the individual
 11 (including information about a request for or receipt
 12 of genetic services by an individual or family member
 13 of such individual).”.

14 (b) *LIMITATIONS ON GENETIC TESTING.*—Section
 15 9802 of the Internal Revenue Code of 1986 is amended by
 16 adding at the end the following:

17 “(d) *GENETIC TESTING AND GENETIC SERVICES.*—

18 “(1) *LIMITATION ON REQUESTING OR REQUIRING*
 19 *GENETIC TESTING.*—A group health plan shall not re-
 20 quest or require an individual or a family member of
 21 such individual to undergo a genetic test.

22 “(2) *RULE OF CONSTRUCTION.*—Nothing in this
 23 part shall be construed to—

24 “(A) limit the authority of a health care
 25 professional who is providing health care services

1 *with respect to an individual to request that*
2 *such individual or a family member of such in-*
3 *dividual undergo a genetic test;*

4 “(B) *limit the authority of a health care*
5 *professional who is employed by or affiliated*
6 *with a group health plan and who is providing*
7 *health care services to an individual as part of*
8 *a bona fide wellness program to notify such indi-*
9 *vidual of the availability of a genetic test or to*
10 *provide information to such individual regard-*
11 *ing such genetic test; or*

12 “(C) *authorize or permit a health care pro-*
13 *fessional to require that an individual undergo a*
14 *genetic test.*

15 “(e) *APPLICATION TO ALL PLANS.—The provisions of*
16 *subsections (a)(1)(F), (b)(3), and (d) shall apply to group*
17 *health plans and health insurance issuers without regard*
18 *to section 9831(a)(2).”.*

19 “(c) *DEFINITIONS.—Section 9832(d) of the Internal*
20 *Revenue Code of 1986 is amended by adding at the end*
21 *the following:*

22 “(6) *FAMILY MEMBER.—The term ‘family mem-*
23 *ber’ means with respect to an individual—*

24 “(A) *the spouse of the individual;*

1 “(B) a dependent child of the individual,
2 including a child who is born to or placed for
3 adoption with the individual; and

4 “(C) all other individuals related by blood
5 to the individual or the spouse or child described
6 in subparagraph (A) or (B).

7 “(7) *GENETIC SERVICES*.—The term ‘genetic
8 services’ means—

9 “(A) a genetic test;

10 “(B) genetic counseling (such as obtaining,
11 interpreting, or assessing genetic information);
12 or

13 “(C) genetic education.

14 “(8) *GENETIC INFORMATION*.—

15 “(A) *IN GENERAL*.—Except as provided in
16 subparagraph (B), the term ‘genetic information’
17 means information about—

18 “(i) an individual’s genetic tests;

19 “(ii) the genetic tests of family mem-
20 bers of the individual; or

21 “(iii) the occurrence of a disease or
22 disorder in family members of the indi-
23 vidual.

1 “(B) *EXCLUSIONS.*—*The term ‘genetic in-*
2 *formation’ shall not include information about*
3 *the sex or age of an individual.*

4 “(9) *GENETIC TEST.*—

5 “(A) *IN GENERAL.*—*The term ‘genetic test’*
6 *means an analysis of human DNA, RNA, chro-*
7 *mosomes, proteins, or metabolites, that detects*
8 *genotypes, mutations, or chromosomal changes.*

9 “(B) *EXCEPTIONS.*—*The term ‘genetic test’*
10 *does not mean—*

11 “(i) *an analysis of proteins or metabo-*
12 *lites that does not detect genotypes,*
13 *mutations, or chromosomal changes; or*

14 “(ii) *an analysis of proteins or me-*
15 *tabolites that is directly related to a mani-*
16 *fested disease, disorder, or pathological con-*
17 *dition that could reasonably be detected by*
18 *a health care professional with appropriate*
19 *training and expertise in the field of medi-*
20 *cine involved.”.*

21 (d) *REGULATIONS AND EFFECTIVE DATE.*—

22 (1) *REGULATIONS.*—*Not later than 1 year after*
23 *the date of enactment of this title, the Secretary of the*
24 *Treasury shall issue final regulations in an accessible*

1 *format to carry out the amendments made by this sec-*
 2 *tion.*

3 (2) *EFFECTIVE DATE.*—*The amendments made*
 4 *by this section shall apply with respect to group*
 5 *health plans for plan years beginning after the date*
 6 *that is 18 months after the date of enactment of this*
 7 *title.*

8 **SEC. 104. AMENDMENTS TO TITLE XVIII OF THE SOCIAL SE-**
 9 **CURITY ACT RELATING TO MEDIGAP.**

10 (a) *NONDISCRIMINATION.*—

11 (1) *IN GENERAL.*—*Section 1882(s)(2) of the So-*
 12 *cial Security Act (42 U.S.C. 1395ss(s)(2)) is amended*
 13 *by adding at the end the following:*

14 “(E)(i) *An issuer of a medicare supple-*
 15 *mental policy shall not deny or condition the*
 16 *issuance or effectiveness of the policy, and shall*
 17 *not discriminate in the pricing of the policy (in-*
 18 *cluding the adjustment of premium rates) of an*
 19 *eligible individual on the basis of genetic infor-*
 20 *mation concerning the individual (or informa-*
 21 *tion about a request for, or the receipt of, genetic*
 22 *services by such individual or family member of*
 23 *such individual).*

24 “(ii) *For purposes of clause (i), the terms*
 25 *‘family member’, ‘genetic services’, and ‘genetic*

1 *information’ shall have the meanings given such*
 2 *terms in subsection (v).”.*

3 (2) *EFFECTIVE DATE.*—*The amendment made by*
 4 *paragraph (1) shall apply with respect to a policy for*
 5 *policy years beginning after the date that is 18*
 6 *months after the date of enactment of this Act.*

7 (b) *LIMITATIONS ON GENETIC TESTING.*—

8 (1) *IN GENERAL.*—*Section 1882 of the Social Se-*
 9 *curity Act (42 U.S.C. 1395ss) is amended by adding*
 10 *at the end the following:*

11 “(v) *LIMITATIONS ON GENETIC TESTING.*—

12 “(1) *GENETIC TESTING.*—

13 “(A) *LIMITATION ON REQUESTING OR RE-*
 14 *QUIRING GENETIC TESTING.*—*An issuer of a*
 15 *medicare supplemental policy shall not request*
 16 *or require an individual or a family member of*
 17 *such individual to undergo a genetic test.*

18 “(B) *RULE OF CONSTRUCTION.*—*Nothing in*
 19 *this title shall be construed to—*

20 “(i) *limit the authority of a health*
 21 *care professional who is providing health*
 22 *care services with respect to an individual*
 23 *to request that such individual or a family*
 24 *member of such individual undergo a ge-*
 25 *netic test;*

1 “(ii) limit the authority of a health
2 care professional who is employed by or af-
3 filiated with an issuer of a medicare supple-
4 mental policy and who is providing health
5 care services to an individual as part of a
6 bona fide wellness program to notify such
7 individual of the availability of a genetic
8 test or to provide information to such indi-
9 vidual regarding such genetic test; or

10 “(iii) authorize or permit a health care
11 professional to require that an individual
12 undergo a genetic test.

13 “(2) DEFINITIONS.—In this subsection:

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

16 “(i) the spouse of the individual;

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

20 “(iii) any other individuals related by
21 blood to the individual or to the spouse or
22 child described in clause (i) or (ii).

23 “(B) GENETIC INFORMATION.—

1 “(i) *IN GENERAL.*—*Except as provided*
2 *in clause (ii), the term ‘genetic information’*
3 *means information about—*

4 “(I) *an individual’s genetic tests;*

5 “(II) *the genetic tests of family*
6 *members of the individual; or*

7 “(III) *the occurrence of a disease*
8 *or disorder in family members of the*
9 *individual.*

10 “(ii) *EXCLUSIONS.*—*The term ‘genetic*
11 *information’ shall not include information*
12 *about the sex or age of an individual.*

13 “(C) *GENETIC TEST.*—

14 “(i) *IN GENERAL.*—*The term ‘genetic*
15 *test’ means an analysis of human DNA,*
16 *RNA, chromosomes, proteins, or metabolites,*
17 *that detects genotypes, mutations, or chro-*
18 *mosomal changes.*

19 “(ii) *EXCEPTIONS.*—*The term ‘genetic*
20 *test’ does not mean—*

21 “(I) *an analysis of proteins or*
22 *metabolites that does not detect*
23 *genotypes, mutations, or chromosomal*
24 *changes; or*

1 “(II) *an analysis of proteins or*
2 *metabolites that is directly related to a*
3 *manifested disease, disorder, or patho-*
4 *logical condition that could reasonably*
5 *be detected by a health care profes-*
6 *sional with appropriate training and*
7 *expertise in the field of medicine in-*
8 *volved.*

9 “(D) *GENETIC SERVICES.*—*The term ‘ge-*
10 *netic services’ means—*

11 “(i) *a genetic test;*

12 “(ii) *genetic counseling (such as ob-*
13 *taining, interpreting, or assessing genetic*
14 *information); or*

15 “(iii) *genetic education.*

16 “(E) *ISSUER OF A MEDICARE SUPPLE-*
17 *MENTAL POLICY.*—*The term ‘issuer of a medicare*
18 *supplemental policy’ includes a third-party ad-*
19 *ministrator or other person acting for or on be-*
20 *half of such issuer.”.*

21 “(2) *CONFORMING AMENDMENT.*—*Section 1882(o)*
22 *of the Social Security Act (42 U.S.C. 1395ss(o)) is*
23 *amended by adding at the end the following:*

1 “(4) *The issuer of the medicare supplemental*
2 *policy complies with subsection (s)(2)(E) and sub-*
3 *section (v).*”.

4 (3) *EFFECTIVE DATE.*—*The amendments made*
5 *by this subsection shall apply with respect to an*
6 *issuer of a medicare supplemental policy for policy*
7 *years beginning on or after the date that is 18 months*
8 *after the date of enactment of this Act.*

9 (c) *TRANSITION PROVISIONS.*—

10 (1) *IN GENERAL.*—*If the Secretary of Health and*
11 *Human Services identifies a State as requiring a*
12 *change to its statutes or regulations to conform its*
13 *regulatory program to the changes made by this sec-*
14 *tion, the State regulatory program shall not be con-*
15 *sidered to be out of compliance with the requirements*
16 *of section 1882 of the Social Security Act due solely*
17 *to failure to make such change until the date specified*
18 *in paragraph (4).*

19 (2) *NAIC STANDARDS.*—*If, not later than June*
20 *30, 2004, the National Association of Insurance Com-*
21 *missioners (in this subsection referred to as the*
22 *“NAIC”) modifies its NAIC Model Regulation relat-*
23 *ing to section 1882 of the Social Security Act (re-*
24 *ferred to in such section as the 1991 NAIC Model*
25 *Regulation, as subsequently modified) to conform to*

1 *the amendments made by this section, such revised*
2 *regulation incorporating the modifications shall be*
3 *considered to be the applicable NAIC model regulation*
4 *(including the revised NAIC model regulation and the*
5 *1991 NAIC Model Regulation) for the purposes of*
6 *such section.*

7 (3) *SECRETARY STANDARDS.—If the NAIC does*
8 *not make the modifications described in paragraph*
9 *(2) within the period specified in such paragraph, the*
10 *Secretary of Health and Human Services shall, not*
11 *later than October 1, 2004, make the modifications*
12 *described in such paragraph and such revised regula-*
13 *tion incorporating the modifications shall be consid-*
14 *ered to be the appropriate regulation for the purposes*
15 *of such section.*

16 (4) *DATE SPECIFIED.—*

17 (A) *IN GENERAL.—Subject to subparagraph*
18 *(B), the date specified in this paragraph for a*
19 *State is the earlier of—*

20 (i) *the date the State changes its stat-*
21 *utes or regulations to conform its regulatory*
22 *program to the changes made by this sec-*
23 *tion, or*

24 (ii) *October 1, 2004.*

1 (B) *ADDITIONAL LEGISLATIVE ACTION RE-*
2 *QUIRED.—In the case of a State which the Sec-*
3 *retary identifies as—*

4 (i) *requiring State legislation (other*
5 *than legislation appropriating funds) to*
6 *conform its regulatory program to the*
7 *changes made in this section, but*

8 (ii) *having a legislature which is not*
9 *scheduled to meet in 2004 in a legislative*
10 *session in which such legislation may be*
11 *considered,*

12 *the date specified in this paragraph is the first*
13 *day of the first calendar quarter beginning after*
14 *the close of the first legislative session of the*
15 *State legislature that begins on or after July 1,*
16 *2004. For purposes of the previous sentence, in*
17 *the case of a State that has a 2-year legislative*
18 *session, each year of such session shall be deemed*
19 *to be a separate regular session of the State legis-*
20 *lature.*

21 **SEC. 105. PRIVACY AND CONFIDENTIALITY.**

22 (a) *APPLICABILITY.—Except as provided in subsection*
23 *(d), the provisions of this section shall apply to group health*
24 *plans, health insurance issuers (including issuers in connec-*
25 *tion with group health plans or individual health coverage),*

1 *and issuers of medicare supplemental policies, without re-*
2 *gard to—*

3 (1) *section 732(a) of the Employee Retirement*
4 *Income Security Act of 1974 (29 U.S.C. 1191a(a));*

5 (2) *section 2721(a) of the Public Health Service*
6 *Act (42 U.S.C. 300gg-21(a)); and*

7 (3) *section 9831(a)(2) of the Internal Revenue*
8 *Code of 1986.*

9 (b) *COMPLIANCE WITH CERTAIN CONFIDENTIALITY*
10 *STANDARDS WITH RESPECT TO GENETIC INFORMATION.—*

11 (1) *IN GENERAL.—The regulations promulgated*
12 *by the Secretary of Health and Human Services*
13 *under part C of title XI of the Social Security Act*
14 *(42 U.S.C. 1320d et seq.) and section 264 of the*
15 *Health Insurance Portability and Accountability Act*
16 *of 1996 (42 U.S.C. 1320d-2 note) shall apply to the*
17 *use or disclosure of genetic information.*

18 (2) *PROHIBITION ON UNDERWRITING AND PRE-*
19 *MIUM RATING.—Notwithstanding paragraph (1), a*
20 *group health plan, a health insurance issuer, or issuer*
21 *of a medicare supplemental policy shall not use or*
22 *disclose genetic information (including information*
23 *about a request for or a receipt of genetic services by*
24 *an individual or family member of such individual)*
25 *for purposes of underwriting, determinations of eligi-*

1 *bility to enroll, premium rating, or the creation, re-*
2 *newal or replacement of a plan, contract or coverage*
3 *for health insurance or health benefits.*

4 *(c) PROHIBITION ON COLLECTION OF GENETIC INFOR-*
5 *MATION.—*

6 *(1) IN GENERAL.—A group health plan, health*
7 *insurance issuer, or issuer of a medicare supple-*
8 *mental policy shall not request, require, or purchase*
9 *genetic information (including information about a*
10 *request for or a receipt of genetic services by an indi-*
11 *vidual or family member of such individual) for pur-*
12 *poses of underwriting, determinations of eligibility to*
13 *enroll, premium rating, or the creation, renewal or*
14 *replacement of a plan, contract or coverage for health*
15 *insurance or health benefits.*

16 *(2) LIMITATION RELATING TO THE COLLECTION*
17 *OF GENETIC INFORMATION PRIOR TO ENROLLMENT.—*
18 *A group health plan, health insurance issuer, or*
19 *issuer of a medicare supplemental policy shall not re-*
20 *quest, require, or purchase genetic information (in-*
21 *cluding information about a request for or a receipt*
22 *of genetic services by an individual or family member*
23 *of such individual) concerning a participant, bene-*
24 *ficiary, or enrollee prior to the enrollment, and in*

1 *connection with such enrollment, of such individual*
2 *under the plan, coverage, or policy.*

3 (3) *INCIDENTAL COLLECTION.*—Where a group
4 *health plan, health insurance issuer, or issuer of a*
5 *medicare supplemental policy obtains genetic infor-*
6 *mation incidental to the requesting, requiring, or*
7 *purchasing of other information concerning a partici-*
8 *pant, beneficiary, or enrollee, such request, require-*
9 *ment, or purchase shall not be considered a violation*
10 *of this subsection if—*

11 (A) *such request, requirement, or purchase*
12 *is not in violation of paragraph (1); and*

13 (B) *any genetic information (including in-*
14 *formation about a request for or receipt of ge-*
15 *netic services) requested, required, or purchased*
16 *is not used or disclosed in violation of subsection*
17 *(b).*

18 (d) *APPLICATION OF CONFIDENTIALITY STANDARDS.*—
19 *The provisions of subsections (b) and (c) shall not apply—*

20 (1) *to group health plans, health insurance*
21 *issuers, or issuers of medicare supplemental policies*
22 *that are not otherwise covered under the regulations*
23 *promulgated by the Secretary of Health and Human*
24 *Services under part C of title XI of the Social Secu-*
25 *rity Act (42 U.S.C. 1320d et seq.) and section 264 of*

1 *the Health Insurance Portability and Accountability*
2 *Act of 1996 (42 U.S.C. 1320d–2 note); and*

3 *(2) to genetic information that is not considered*
4 *to be individually-identifiable health information*
5 *under the regulations promulgated by the Secretary of*
6 *Health and Human Services under part C of title XI*
7 *of the Social Security Act (42 U.S.C. 1320d et seq.)*
8 *and section 264 of the Health Insurance Portability*
9 *and Accountability Act of 1996 (42 U.S.C. 1320d–2*
10 *note).*

11 *(e) ENFORCEMENT.—A group health plan, health in-*
12 *surance issuer, or issuer of a medicare supplemental policy*
13 *that violates a provision of this section shall be subject to*
14 *the penalties described in sections 1176 and 1177 of the So-*
15 *cial Security Act (42 U.S.C. 1320d–5 and 1320d–6) in the*
16 *same manner and to the same extent that such penalties*
17 *apply to violations of part C of title XI of such Act.*

18 *(f) PREEMPTION.—*

19 *(1) IN GENERAL.—A provision or requirement*
20 *under this section or a regulation promulgated under*
21 *this section shall supersede any contrary provision of*
22 *State law unless such provision of State law imposes*
23 *requirements, standards, or implementation specifica-*
24 *tions that are more stringent than the requirements,*
25 *standards, or implementation specifications imposed*

1 *under this section or such regulations. No penalty,*
2 *remedy, or cause of action to enforce such a State*
3 *law that is more stringent shall be preempted by this*
4 *section.*

5 (2) *RULE OF CONSTRUCTION.—Nothing in para-*
6 *graph (1) shall be construed to establish a penalty,*
7 *remedy, or cause of action under State law if such*
8 *penalty, remedy, or cause of action is not otherwise*
9 *available under such State law.*

10 (g) *COORDINATION WITH PRIVACY REGULATIONS.—*
11 *The Secretary shall implement and administer this section*
12 *in a manner that is consistent with the implementation and*
13 *administration by the Secretary of the regulations promul-*
14 *gated by the Secretary of Health and Human Services*
15 *under part C of title XI of the Social Security Act (42*
16 *U.S.C. 1320d et seq.) and section 264 of the Health Insur-*
17 *ance Portability and Accountability Act of 1996 (42 U.S.C.*
18 *1320d–2 note).*

19 (h) *DEFINITIONS.—In this section:*

20 (1) *GENETIC INFORMATION; GENETIC SERV-*
21 *ICES.—The terms “family member”, “genetic infor-*
22 *mation”, “genetic services”, and “genetic test” have*
23 *the meanings given such terms in section 2791 of the*
24 *Public Health Service Act (42 U.S.C. 300gg–91), as*
25 *amended by this Act.*

1 (2) *GROUP HEALTH PLAN; HEALTH INSURANCE*
 2 *ISSUER.*—*The terms “group health plan” and “health*
 3 *insurance issuer” include only those plans and issuers*
 4 *that are covered under the regulations described in*
 5 *subsection (d)(1).*

6 (3) *ISSUER OF A MEDICARE SUPPLEMENTAL POL-*
 7 *ICY.*—*The term “issuer of a medicare supplemental*
 8 *policy” means an issuer described in section 1882 of*
 9 *the Social Security Act (42 insert 1395ss).*

10 (4) *SECRETARY.*—*The term “Secretary” means*
 11 *the Secretary of Health and Human Services.*

12 **SEC. 106. ASSURING COORDINATION.**

13 (a) *IN GENERAL.*—*Except as provided in subsection*
 14 *(b), the Secretary of the Treasury, the Secretary of Health*
 15 *and Human Services, and the Secretary of Labor shall en-*
 16 *sure, through the execution of an interagency memorandum*
 17 *of understanding among such Secretaries, that—*

18 (1) *regulations, rulings, and interpretations*
 19 *issued by such Secretaries relating to the same matter*
 20 *over which two or more such Secretaries have respon-*
 21 *sibility under this title (and the amendments made by*
 22 *this title) are administered so as to have the same ef-*
 23 *fect at all times; and*

24 (2) *coordination of policies relating to enforcing*
 25 *the same requirements through such Secretaries in*

1 *order to have a coordinated enforcement strategy that*
 2 *avoids duplication of enforcement efforts and assigns*
 3 *priorities in enforcement.*

4 *(b) AUTHORITY OF THE SECRETARY.—The Secretary*
 5 *of Health and Human Services has the sole authority to*
 6 *promulgate regulations to implement section 105.*

7 **SEC. 107. REGULATIONS; EFFECTIVE DATE.**

8 *(a) REGULATIONS.—Not later than 1 year after the*
 9 *date of enactment of this title, the Secretary of Labor, the*
 10 *Secretary of Health and Human Services, and the Sec-*
 11 *retary of the Treasury shall issue final regulations in an*
 12 *accessible format to carry out this title.*

13 *(b) EFFECTIVE DATE.—Except as provided in section*
 14 *104, the amendments made by this title shall take effect on*
 15 *the date that is 18 months after the date of enactment of*
 16 *this Act.*

17 **TITLE II—PROHIBITING EMPLOY-**
 18 **MENT DISCRIMINATION ON**
 19 **THE BASIS OF GENETIC IN-**
 20 **FORMATION**

21 **SEC. 201. DEFINITIONS.**

22 *In this title:*

23 *(1) COMMISSION.—The term “Commission”*
 24 *means the Equal Employment Opportunity Commis-*

1 *sion as created by section 705 of the Civil Rights Act*
2 *of 1964 (42 U.S.C. 2000e-4).*

3 (2) *EMPLOYEE; EMPLOYER; EMPLOYMENT*
4 *AGENCY; LABOR ORGANIZATION; MEMBER.—*

5 (A) *IN GENERAL.—The term “employee”*
6 *means—*

7 (i) *an employee (including an appli-*
8 *cant), as defined in section 701(f) of the*
9 *Civil Rights Act of 1964 (42 U.S.C.*
10 *2000e(f));*

11 (ii) *a State employee (including an*
12 *applicant) described in section 304(a) of the*
13 *Government Employee Rights Act of 1991*
14 *(42 U.S.C. 2000e-16c(a));*

15 (iii) *a covered employee (including an*
16 *applicant), as defined in section 101 of the*
17 *Congressional Accountability Act of 1995 (2*
18 *U.S.C. 1301);*

19 (iv) *a covered employee (including an*
20 *applicant), as defined in section 411(c) of*
21 *title 3, United States Code; or*

22 (v) *an employee or applicant to which*
23 *section 717(a) of the Civil Rights Act of*
24 *1964 (42 U.S.C. 2000e-16(a)) applies.*

1 (B) *EMPLOYER.*—*The term “employer”*
2 *means—*

3 (i) *an employer (as defined in section*
4 *701(b) of the Civil Rights Act of 1964 (42*
5 *U.S.C. 2000e(b));*

6 (ii) *an entity employing a State em-*
7 *ployee described in section 304(a) of the*
8 *Government Employee Rights Act of 1991;*

9 (iii) *an employing office, as defined in*
10 *section 101 of the Congressional Account-*
11 *ability Act of 1995;*

12 (iv) *an employing office, as defined in*
13 *section 411(c) of title 3, United States Code;*
14 *or*

15 (v) *an entity to which section 717(a) of*
16 *the Civil Rights Act of 1964 applies.*

17 (C) *EMPLOYMENT AGENCY; LABOR ORGANI-*
18 *ZATION.*—*The terms “employment agency” and*
19 *“labor organization” have the meanings given*
20 *the terms in section 701 of the Civil Rights Act*
21 *of 1964 (42 U.S.C. 2000e).*

22 (D) *MEMBER.*—*The term “member”, with*
23 *respect to a labor organization, includes an ap-*
24 *plicant for membership in a labor organization.*

1 (3) *FAMILY MEMBER.*—*The term “family mem-*
2 *ber” means with respect to an individual—*

3 (A) *the spouse of the individual;*

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

7 (C) *all other individuals related by blood to*
8 *the individual or the spouse or child described in*
9 *subparagraph (A) or (B).*

10 (4) *GENETIC INFORMATION.*—

11 (A) *IN GENERAL.*—*Except as provided in*
12 *subparagraph (B), the term “genetic informa-*
13 *tion” means information about—*

14 (i) *an individual’s genetic tests;*

15 (ii) *the genetic tests of family members*
16 *of the individual; or*

17 (iii) *the occurrence of a disease or dis-*
18 *order in family members of the individual.*

19 (B) *EXCEPTIONS.*—*The term “genetic infor-*
20 *mation” shall not include information about the*
21 *sex or age of an individual.*

22 (5) *GENETIC MONITORING.*—*The term “genetic*
23 *monitoring” means the periodic examination of em-*
24 *ployees to evaluate acquired modifications to their ge-*
25 *netic material, such as chromosomal damage or evi-*

1 *dence of increased occurrence of mutations, that may*
2 *have developed in the course of employment due to ex-*
3 *posure to toxic substances in the workplace, in order*
4 *to identify, evaluate, and respond to the effects of or*
5 *control adverse environmental exposures in the work-*
6 *place.*

7 (6) *GENETIC SERVICES.*—*The term “genetic serv-*
8 *ices” means—*

9 (A) *a genetic test;*

10 (B) *genetic counseling (such as obtaining,*
11 *interpreting or assessing genetic information); or*

12 (C) *genetic education.*

13 (7) *GENETIC TEST.*—

14 (A) *IN GENERAL.*—*The term “genetic test”*
15 *means the analysis of human DNA, RNA, chro-*
16 *mosomes, proteins, or metabolites, that detects*
17 *genotypes, mutations, or chromosomal changes.*

18 (B) *EXCEPTION.*—*The term “genetic test”*
19 *does not mean an analysis of proteins or metabo-*
20 *lites that does not detect genotypes, mutations, or*
21 *chromosomal changes.*

22 **SEC. 202. EMPLOYER PRACTICES.**

23 (a) *USE OF GENETIC INFORMATION.*—*It shall be an*
24 *unlawful employment practice for an employer—*

1 (1) *to fail or refuse to hire or to discharge any*
2 *employee, or otherwise to discriminate against any*
3 *employee with respect to the compensation, terms,*
4 *conditions, or privileges of employment of the em-*
5 *ployee, because of genetic information with respect to*
6 *the employee (or information about a request for or*
7 *the receipt of genetic services by such employee or*
8 *family member of such employee); or*

9 (2) *to limit, segregate, or classify the employees*
10 *of the employer in any way that would deprive or*
11 *tend to deprive any employee of employment opportu-*
12 *nities or otherwise adversely affect the status of the*
13 *employee as an employee, because of genetic informa-*
14 *tion with respect to the employee (or information*
15 *about a request for or the receipt of genetic services*
16 *by such employee or family member of such em-*
17 *ployee).*

18 (b) *ACQUISITION OF GENETIC INFORMATION.—It shall*
19 *be an unlawful employment practice for an employer to re-*
20 *quest, require, or purchase genetic information with respect*
21 *to an employee or a family member of the employee (or in-*
22 *formation about a request for the receipt of genetic services*
23 *by such employee or a family member of such employee)*
24 *except—*

1 (1) *where an employer inadvertently requests or*
2 *requires family medical history of the employee or*
3 *family member of the employee;*

4 (2) *where—*

5 (A) *health or genetic services are offered by*
6 *the employer, including such services offered as*
7 *part of a bona fide wellness program;*

8 (B) *the employee provides prior, knowing,*
9 *voluntary, and written authorization;*

10 (C) *only the employee (or family member if*
11 *the family member is receiving genetic services)*
12 *and the licensed health care professional or board*
13 *certified genetic counselor involved in providing*
14 *such services receive individually identifiable in-*
15 *formation concerning the results of such services;*
16 *and*

17 (D) *any individually identifiable genetic*
18 *information provided under subparagraph (C) in*
19 *connection with the services provided under sub-*
20 *paragraph (A) is only available for purposes of*
21 *such services and shall not be disclosed to the em-*
22 *ployer except in aggregate terms that do not dis-*
23 *close the identity of specific employees;*

24 (3) *where an employer requests or requires fam-*
25 *ily medical history from the employee to comply with*

1 *the certification provisions of section 103 of the Fam-*
2 *ily and Medical Leave Act of 1993 (29 U.S.C. 2613)*
3 *or such requirements under State family and medical*
4 *leave laws;*

5 *(4) where an employer purchases documents that*
6 *are commercially and publicly available (including*
7 *newspapers, magazines, periodicals, and books, but*
8 *not including medical databases or court records) that*
9 *include family medical history; or*

10 *(5) where the information involved is to be used*
11 *for genetic monitoring of the biological effects of toxic*
12 *substances in the workplace, but only if—*

13 *(A) the employer provides written notice of*
14 *the genetic monitoring to the employee;*

15 *(B)(i) the employee provides prior, know-*
16 *ing, voluntary, and written authorization; or*

17 *(ii) the genetic monitoring is required by*
18 *Federal or State law;*

19 *(C) the employee is informed of individual*
20 *monitoring results;*

21 *(D) the monitoring is in compliance with—*

22 *(i) any Federal genetic monitoring reg-*
23 *ulations, including any such regulations*
24 *that may be promulgated by the Secretary*
25 *of Labor pursuant to the Occupational*

1 *Safety and Health Act of 1970 (29 U.S.C.*
 2 *651 et seq.), the Federal Mine Safety and*
 3 *Health Act of 1977 (30 U.S.C. 801 et seq.),*
 4 *or the Atomic Energy Act of 1954 (42*
 5 *U.S.C. 2011 et seq.); or*

6 *(ii) State genetic monitoring regula-*
 7 *tions, in the case of a State that is imple-*
 8 *menting genetic monitoring regulations*
 9 *under the authority of the Occupational*
 10 *Safety and Health Act of 1970 (29 U.S.C.*
 11 *651 et seq.); and*

12 *(E) the employer, excluding any licensed*
 13 *health care professional or board certified genetic*
 14 *counselor that is involved in the genetic moni-*
 15 *toring program, receives the results of the moni-*
 16 *toring only in aggregate terms that do not dis-*
 17 *close the identity of specific employees;*

18 *(c) PRESERVATION OF PROTECTIONS.—In the case of*
 19 *information to which any of paragraphs (1) through (5)*
 20 *of subsection (b) applies, such information may not be used*
 21 *in violation of paragraph (1) or (2) of subsection (a) or*
 22 *treated or disclosed in a manner that violates section 206.*

23 **SEC. 203. EMPLOYMENT AGENCY PRACTICES.**

24 *(a) USE OF GENETIC INFORMATION.—It shall be an*
 25 *unlawful employment practice for an employment agency—*

1 (1) to fail or refuse to refer for employment, or
2 otherwise to discriminate against, any individual be-
3 cause of genetic information with respect to the indi-
4 vidual (or information about a request for or the re-
5 ceipt of genetic services by such individual or family
6 member of such individual);

7 (2) to limit, segregate, or classify individuals or
8 fail or refuse to refer for employment any individual
9 in any way that would deprive or tend to deprive any
10 individual of employment opportunities, or otherwise
11 adversely affect the status of the individual as an em-
12 ployee, because of genetic information with respect to
13 the individual (or information about a request for or
14 the receipt of genetic services by such individual or
15 family member of such individual); or

16 (3) to cause or attempt to cause an employer to
17 discriminate against an individual in violation of
18 this title.

19 (b) ACQUISITION OF GENETIC INFORMATION.—It shall
20 be an unlawful employment practice for an employment
21 agency to request, require, or purchase genetic information
22 with respect to an individual or a family member of the
23 individual (or information about a request for the receipt
24 of genetic services by such individual or a family member
25 of such individual) except—

1 (1) *where an employment agency inadvertently*
2 *requests or requires family medical history of the in-*
3 *dividual or family member of the individual;*

4 (2) *where—*

5 (A) *health or genetic services are offered by*
6 *the employment agency, including such services*
7 *offered as part of a bona fide wellness program;*

8 (B) *the individual provides prior, knowing,*
9 *voluntary, and written authorization;*

10 (C) *only the individual (or family member*
11 *if the family member is receiving genetic serv-*
12 *ices) and the licensed health care professional or*
13 *board certified genetic counselor involved in pro-*
14 *viding such services receive individually identifi-*
15 *able information concerning the results of such*
16 *services; and*

17 (D) *any individually identifiable genetic*
18 *information provided under subparagraph (C) in*
19 *connection with the services provided under sub-*
20 *paragraph (A) is only available for purposes of*
21 *such services and shall not be disclosed to the em-*
22 *ployment agency except in aggregate terms that*
23 *do not disclose the identity of specific individ-*
24 *uals;*

1 (3) where an employment agency requests or re-
2 quires family medical history from the individual to
3 comply with the certification provisions of section 103
4 of the Family and Medical Leave Act of 1993 (29
5 U.S.C. 2613) or such requirements under State family
6 and medical leave laws;

7 (4) where an employment agency purchases doc-
8 uments that are commercially and publicly available
9 (including newspapers, magazines, periodicals, and
10 books, but not including medical databases or court
11 records) that include family medical history; or

12 (5) where the information involved is to be used
13 for genetic monitoring of the biological effects of toxic
14 substances in the workplace, but only if—

15 (A) the employment agency provides written
16 notice of the genetic monitoring to the indi-
17 vidual;

18 (B)(i) the individual provides prior, know-
19 ing, voluntary, and written authorization; or

20 (ii) the genetic monitoring is required by
21 Federal or State law;

22 (C) the individual is informed of individual
23 monitoring results;

24 (D) the monitoring is in compliance with—

1 (i) any Federal genetic monitoring reg-
2 ulations, including any such regulations
3 that may be promulgated by the Secretary
4 of Labor pursuant to the Occupational
5 Safety and Health Act of 1970 (29 U.S.C.
6 651 et seq.), the Federal Mine Safety and
7 Health Act of 1977 (30 U.S.C. 801 et seq.),
8 or the Atomic Energy Act of 1954 (42
9 U.S.C. 2011 et seq.); or

10 (ii) State genetic monitoring regula-
11 tions, in the case of a State that is imple-
12 menting genetic monitoring regulations
13 under the authority of the Occupational
14 Safety and Health Act of 1970 (29 U.S.C.
15 651 et seq.); and

16 (E) the employment agency, excluding any
17 licensed health care professional or board cer-
18 tified genetic counselor that is involved in the ge-
19 netic monitoring program, receives the results of
20 the monitoring only in aggregate terms that do
21 not disclose the identity of specific individuals;

22 (c) *PRESERVATION OF PROTECTIONS.*—In the case of
23 information to which any of paragraphs (1) through (5)
24 of subsection (b) applies, such information may not be used

1 *in violation of paragraph (1) or (2) of subsection (a) or*
2 *treated or disclosed in a manner that violates section 206.*

3 **SEC. 204. LABOR ORGANIZATION PRACTICES.**

4 (a) *USE OF GENETIC INFORMATION.—It shall be an*
5 *unlawful employment practice for a labor organization—*

6 (1) *to exclude or to expel from the membership*
7 *of the organization, or otherwise to discriminate*
8 *against, any member because of genetic information*
9 *with respect to the member (or information about a*
10 *request for or the receipt of genetic services by such*
11 *member or family member of such member);*

12 (2) *to limit, segregate, or classify the members of*
13 *the organization, or fail or refuse to refer for employ-*
14 *ment any member, in any way that would deprive or*
15 *tend to deprive any member of employment opportu-*
16 *nities, or otherwise adversely affect the status of the*
17 *member as an employee, because of genetic informa-*
18 *tion with respect to the member (or information about*
19 *a request for or the receipt of genetic services by such*
20 *member or family member of such member); or*

21 (3) *to cause or attempt to cause an employer to*
22 *discriminate against a member in violation of this*
23 *title.*

24 (b) *ACQUISITION OF GENETIC INFORMATION.—It shall*
25 *be an unlawful employment practice for a labor organiza-*

1 *tion to request, require, or purchase genetic information*
2 *with respect to a member or a family member of the member*
3 *(or information about a request for the receipt of genetic*
4 *services by such member or a family member of such mem-*
5 *ber) except—*

6 *(1) where a labor organization inadvertently re-*
7 *quests or requires family medical history of the mem-*
8 *ber or family member of the member;*

9 *(2) where—*

10 *(A) health or genetic services are offered by*
11 *the labor organization, including such services*
12 *offered as part of a bona fide wellness program;*

13 *(B) the member provides prior, knowing,*
14 *voluntary, and written authorization;*

15 *(C) only the member (or family member if*
16 *the family member is receiving genetic services)*
17 *and the licensed health care professional or board*
18 *certified genetic counselor involved in providing*
19 *such services receive individually identifiable in-*
20 *formation concerning the results of such services;*
21 *and*

22 *(D) any individually identifiable genetic*
23 *information provided under subparagraph (C) in*
24 *connection with the services provided under sub-*
25 *paragraph (A) is only available for purposes of*

1 *such services and shall not be disclosed to the*
2 *labor organization except in aggregate terms that*
3 *do not disclose the identity of specific members;*

4 (3) *where a labor organization requests or re-*
5 *quires family medical history from the members to*
6 *comply with the certification provisions of section 103*
7 *of the Family and Medical Leave Act of 1993 (29*
8 *U.S.C. 2613) or such requirements under State family*
9 *and medical leave laws;*

10 (4) *where a labor organization purchases docu-*
11 *ments that are commercially and publicly available*
12 *(including newspapers, magazines, periodicals, and*
13 *books, but not including medical databases or court*
14 *records) that include family medical history; or*

15 (5) *where the information involved is to be used*
16 *for genetic monitoring of the biological effects of toxic*
17 *substances in the workplace, but only if—*

18 (A) *the labor organization provides written*
19 *notice of the genetic monitoring to the member;*

20 (B)(i) *the member provides prior, knowing,*
21 *voluntary, and written authorization; or*

22 (ii) *the genetic monitoring is required by*
23 *Federal or State law;*

24 (C) *the member is informed of individual*
25 *monitoring results;*

1 (D) the monitoring is in compliance with—

2 (i) any Federal genetic monitoring reg-
3 ulations, including any such regulations
4 that may be promulgated by the Secretary
5 of Labor pursuant to the Occupational
6 Safety and Health Act of 1970 (29 U.S.C.
7 651 et seq.), the Federal Mine Safety and
8 Health Act of 1977 (30 U.S.C. 801 et seq.),
9 or the Atomic Energy Act of 1954 (42
10 U.S.C. 2011 et seq.); or

11 (ii) State genetic monitoring regula-
12 tions, in the case of a State that is imple-
13 menting genetic monitoring regulations
14 under the authority of the Occupational
15 Safety and Health Act of 1970 (29 U.S.C.
16 651 et seq.); and

17 (E) the labor organization, excluding any
18 licensed health care professional or board cer-
19 tified genetic counselor that is involved in the ge-
20 netic monitoring program, receives the results of
21 the monitoring only in aggregate terms that do
22 not disclose the identity of specific members;

23 (c) *PRESERVATION OF PROTECTIONS.*—In the case of
24 information to which any of paragraphs (1) through (5)
25 of subsection (b) applies, such information may not be used

1 *in violation of paragraph (1) or (2) of subsection (a) or*
2 *treated or disclosed in a manner that violates section 206.*

3 **SEC. 205. TRAINING PROGRAMS.**

4 (a) *USE OF GENETIC INFORMATION.—It shall be an*
5 *unlawful employment practice for any employer, labor or-*
6 *ganization, or joint labor-management committee control-*
7 *ling apprenticeship or other training or retraining, includ-*
8 *ing on-the-job training programs—*

9 (1) *to discriminate against any individual be-*
10 *cause of genetic information with respect to the indi-*
11 *vidual (or information about a request for or the re-*
12 *ceipt of genetic services by such individual or a fam-*
13 *ily member of such individual) in admission to, or*
14 *employment in, any program established to provide*
15 *apprenticeship or other training or retraining;*

16 (2) *to limit, segregate, or classify the applicants*
17 *for or participants in such apprenticeship or other*
18 *training or retraining, or fail or refuse to refer for*
19 *employment any individual, in any way that would*
20 *deprive or tend to deprive any individual of employ-*
21 *ment opportunities, or otherwise adversely affect the*
22 *status of the individual as an employee, because of ge-*
23 *netic information with respect to the individual (or*
24 *information about a request for or receipt of genetic*

1 *services by such individual or family member of such*
2 *individual); or*

3 *(3) to cause or attempt to cause an employer to*
4 *discriminate against an applicant for or a partici-*
5 *part in such apprenticeship or other training or re-*
6 *training in violation of this title.*

7 *(b) ACQUISITION OF GENETIC INFORMATION.—It shall*
8 *be an unlawful employment practice for an employer, labor*
9 *organization, or joint labor-management committee de-*
10 *scribed in subsection (a) to request, require, or purchase ge-*
11 *netic information with respect to an individual or a family*
12 *member of the individual (or information about a request*
13 *for the receipt of genetic services by such individual or a*
14 *family member of such individual) except—*

15 *(1) where the employer, labor organization, or*
16 *joint labor-management committee inadvertently re-*
17 *quests or requires family medical history of the indi-*
18 *vidual or family member of the individual;*

19 *(2) where—*

20 *(A) health or genetic services are offered by*
21 *the employer, labor organization, or joint labor-*
22 *management committee, including such services*
23 *offered as part of a bona fide wellness program;*

24 *(B) the individual provides prior, knowing,*
25 *voluntary, and written authorization;*

1 (C) only the individual (or family member
2 if the family member is receiving genetic serv-
3 ices) and the licensed health care professional or
4 board certified genetic counselor involved in pro-
5 viding such services receive individually identifi-
6 able information concerning the results of such
7 services;

8 (D) any individually identifiable genetic
9 information provided under subparagraph (C) in
10 connection with the services provided under sub-
11 paragraph (A) is only available for purposes of
12 such services and shall not be disclosed to the em-
13 ployer, labor organization, or joint labor-man-
14 agement committee except in aggregate terms
15 that do not disclose the identity of specific indi-
16 viduals;

17 (3) where the employer, labor organization, or
18 joint labor-management committee requests or re-
19 quires family medical history from the individual to
20 comply with the certification provisions of section 103
21 of the Family and Medical Leave Act of 1993 (29
22 U.S.C. 2613) or such requirements under State family
23 and medical leave laws;

24 (4) where the employer, labor organization, or
25 joint labor-management committee purchases docu-

1 *ments that are commercially and publicly available*
2 *(including newspapers, magazines, periodicals, and*
3 *books, but not including medical databases or court*
4 *records) that include family medical history; or*

5 *(5) where the information involved is to be used*
6 *for genetic monitoring of the biological effects of toxic*
7 *substances in the workplace, but only if—*

8 *(A) the employer, labor organization, or*
9 *joint labor-management committee provides*
10 *written notice of the genetic monitoring to the*
11 *individual;*

12 *(B)(i) the individual provides prior, know-*
13 *ing, voluntary, and written authorization; or*

14 *(ii) the genetic monitoring is required by*
15 *Federal or State law;*

16 *(C) the individual is informed of individual*
17 *monitoring results;*

18 *(D) the monitoring is in compliance with—*

19 *(i) any Federal genetic monitoring reg-*
20 *ulations, including any such regulations*
21 *that may be promulgated by the Secretary*
22 *of Labor pursuant to the Occupational*
23 *Safety and Health Act of 1970 (29 U.S.C.*
24 *651 et seq.), the Federal Mine Safety and*
25 *Health Act of 1977 (30 U.S.C. 801 et seq.),*

1 or the Atomic Energy Act of 1954 (42
2 U.S.C. 2011 et seq.); or

3 (ii) State genetic monitoring regula-
4 tions, in the case of a State that is imple-
5 menting genetic monitoring regulations
6 under the authority of the Occupational
7 Safety and Health Act of 1970 (29 U.S.C.
8 651 et seq.); and

9 (E) the employer, labor organization, or
10 joint labor-management committee, excluding
11 any licensed health care professional or board
12 certified genetic counselor that is involved in the
13 genetic monitoring program, receives the results
14 of the monitoring only in aggregate terms that
15 do not disclose the identity of specific individ-
16 uals;

17 (c) *PRESERVATION OF PROTECTIONS.*—In the case of
18 information to which any of paragraphs (1) through (5)
19 of subsection (b) applies, such information may not be used
20 in violation of paragraph (1) or (2) of subsection (a) or
21 treated or disclosed in a manner that violates section 206.

22 **SEC. 206. CONFIDENTIALITY OF GENETIC INFORMATION.**

23 (a) *TREATMENT OF INFORMATION AS PART OF CON-*
24 *FIDENTIAL MEDICAL RECORD.*—If an employer, employ-
25 ment agency, labor organization, or joint labor-manage-

1 *ment committee possesses genetic information about an em-*
2 *ployee or member (or information about a request for or*
3 *receipt of genetic services by such employee or member or*
4 *family member of such employee or member), such informa-*
5 *tion shall be maintained on separate forms and in separate*
6 *medical files and be treated as a confidential medical record*
7 *of the employee or member.*

8 **(b) LIMITATION ON DISCLOSURE.**—*An employer, em-*
9 *ployment agency, labor organization, or joint labor-man-*
10 *agement committee shall not disclose genetic information*
11 *concerning an employee or member (or information about*
12 *a request for or receipt of genetic services by such employee*
13 *or member or family member of such employee or member)*
14 *except—*

15 *(1) to the employee (or family member if the*
16 *family member is receiving the genetic services) or*
17 *member of a labor organization at the request of the*
18 *employee or member of such organization;*

19 *(2) to an occupational or other health researcher*
20 *if the research is conducted in compliance with the*
21 *regulations and protections provided for under part*
22 *46 of title 45, Code of Federal Regulations;*

23 *(3) in response to an order of a court, except*
24 *that—*

1 (A) the employer, employment agency, labor
2 organization, or joint labor-management com-
3 mittee may disclose only the genetic information
4 expressly authorized by such order; and

5 (B) if the court order was secured without
6 the knowledge of the employee or member to
7 whom the information refers, the employer, em-
8 ployment agency, labor organization, or joint
9 labor-management committee shall provide the
10 employee or member with adequate notice to
11 challenge the court order;

12 (4) to government officials who are investigating
13 compliance with this title if the information is rel-
14 evant to the investigation; or

15 (5) to the extent that such disclosure is made in
16 connection with the employee's compliance with the
17 certification provisions of section 103 of the Family
18 and Medical Leave Act of 1993 (29 U.S.C. 2613) or
19 such requirements under State family and medical
20 leave laws.

21 **SEC. 207. REMEDIES AND ENFORCEMENT.**

22 (a) *EMPLOYEES COVERED BY TITLE VII OF THE CIVIL*
23 *RIGHTS ACT OF 1964.*—

24 (1) *IN GENERAL.*—The powers, remedies, and
25 procedures provided in sections 705, 706, 707, 709,

1 710, and 711 of the Civil Rights Act of 1964 (42
2 U.S.C. 2000e–4 et seq.) to the Commission, the Attor-
3 ney General, or any person, alleging a violation of
4 title VII of that Act (42 U.S.C. 2000e et seq.) shall
5 be the powers, remedies, and procedures this title pro-
6 vides to the Commission, the Attorney General, or
7 any person, respectively, alleging an unlawful em-
8 ployment practice in violation of this title against an
9 employee described in section 201(2)(A)(i), except as
10 provided in paragraphs (2) and (3).

11 (2) *COSTS AND FEES.*—The powers, remedies,
12 and procedures provided in subsections (b) and (c) of
13 section 722 of the Revised Statutes (42 U.S.C. 1988),
14 shall be powers, remedies, and procedures this title
15 provides to the Commission, the Attorney General, or
16 any person, alleging such a practice.

17 (3) *DAMAGES.*—The powers, remedies, and pro-
18 cedures provided in section 1977A of the Revised
19 Statutes (42 U.S.C. 1981a), including the limitations
20 contained in subsection (b)(3) of such section 1977A,
21 shall be powers, remedies, and procedures this title
22 provides to the Commission, the Attorney General, or
23 any person, alleging such a practice (not an employ-
24 ment practice specifically excluded from coverage
25 under section 1977A(a)(1) of the Revised Statutes).

1 (b) *EMPLOYEES COVERED BY GOVERNMENT EM-*
2 *PLOYEE RIGHTS ACT OF 1991.—*

3 (1) *IN GENERAL.—The powers, remedies, and*
4 *procedures provided in sections 302 and 304 of the*
5 *Government Employee Rights Act of 1991 (42 U.S.C.*
6 *2000e–16b, 2000e–16c) to the Commission, or any*
7 *person, alleging a violation of section 302(a)(1) of*
8 *that Act (42 U.S.C. 2000e–16b(a)(1)) shall be the*
9 *powers, remedies, and procedures this title provides to*
10 *the Commission, or any person, respectively, alleging*
11 *an unlawful employment practice in violation of this*
12 *title against an employee described in section*
13 *201(2)(A)(ii), except as provided in paragraphs (2)*
14 *and (3).*

15 (2) *COSTS AND FEES.—The powers, remedies,*
16 *and procedures provided in subsections (b) and (c) of*
17 *section 722 of the Revised Statutes (42 U.S.C. 1988),*
18 *shall be powers, remedies, and procedures this title*
19 *provides to the Commission, or any person, alleging*
20 *such a practice.*

21 (3) *DAMAGES.—The powers, remedies, and pro-*
22 *cedures provided in section 1977A of the Revised*
23 *Statutes (42 U.S.C. 1981a), including the limitations*
24 *contained in subsection (b)(3) of such section 1977A,*
25 *shall be powers, remedies, and procedures this title*

1 provides to the Commission, or any person, alleging
2 such a practice (not an employment practice specifi-
3 cally excluded from coverage under section
4 1977A(a)(1) of the Revised Statutes).

5 (c) EMPLOYEES COVERED BY CONGRESSIONAL AC-
6 COUNTABILITY ACT OF 1995.—

7 (1) IN GENERAL.—The powers, remedies, and
8 procedures provided in the Congressional Account-
9 ability Act of 1995 (2 U.S.C. 1301 et seq.) to the
10 Board (as defined in section 101 of that Act (2 U.S.C.
11 1301)), or any person, alleging a violation of section
12 201(a)(1) of that Act (42 U.S.C. 1311(a)(1)) shall be
13 the powers, remedies, and procedures this title pro-
14 vides to that Board, or any person, alleging an un-
15 lawful employment practice in violation of this title
16 against an employee described in section
17 201(2)(A)(iii), except as provided in paragraphs (2)
18 and (3).

19 (2) COSTS AND FEES.—The powers, remedies,
20 and procedures provided in subsections (b) and (c) of
21 section 722 of the Revised Statutes (42 U.S.C. 1988),
22 shall be powers, remedies, and procedures this title
23 provides to that Board, or any person, alleging such
24 a practice.

1 (3) *DAMAGES.*—*The powers, remedies, and pro-*
2 *cedures provided in section 1977A of the Revised*
3 *Statutes (42 U.S.C. 1981a), including the limitations*
4 *contained in subsection (b)(3) of such section 1977A,*
5 *shall be powers, remedies, and procedures this title*
6 *provides to that Board, or any person, alleging such*
7 *a practice (not an employment practice specifically*
8 *excluded from coverage under section 1977A(a)(1) of*
9 *the Revised Statutes).*

10 (4) *OTHER APPLICABLE PROVISIONS.*—*With re-*
11 *spect to a claim alleging a practice described in para-*
12 *graph (1), title III of the Congressional Account-*
13 *ability Act of 1995 (2 U.S.C. 1381 et seq.) shall apply*
14 *in the same manner as such title applies with respect*
15 *to a claim alleging a violation of section 201(a)(1) of*
16 *such Act (2 U.S.C. 1311(a)(1)).*

17 (d) *EMPLOYEES COVERED BY CHAPTER 5 OF TITLE*
18 *3, UNITED STATES CODE.*—

19 (1) *IN GENERAL.*—*The powers, remedies, and*
20 *procedures provided in chapter 5 of title 3, United*
21 *States Code, to the President, the Commission, the*
22 *Merit Systems Protection Board, or any person, alleg-*
23 *ing a violation of section 411(a)(1) of that title, shall*
24 *be the powers, remedies, and procedures this title pro-*
25 *vides to the President, the Commission, such Board,*

1 or any person, respectively, alleging an unlawful em-
2 ployment practice in violation of this title against an
3 employee described in section 201(2)(A)(iv), except as
4 provided in paragraphs (2) and (3).

5 (2) *COSTS AND FEES.*—The powers, remedies,
6 and procedures provided in subsections (b) and (c) of
7 section 722 of the Revised Statutes (42 U.S.C. 1988),
8 shall be powers, remedies, and procedures this title
9 provides to the the President, the Commission, such
10 Board, or any person, alleging such a practice.

11 (3) *DAMAGES.*—The powers, remedies, and pro-
12 cedures provided in section 1977A of the Revised
13 Statutes (42 U.S.C. 1981a), including the limitations
14 contained in subsection (b)(3) of such section 1977A,
15 shall be powers, remedies, and procedures this title
16 provides to the President, the Commission, such
17 Board, or any person, alleging such a practice (not
18 an employment practice specifically excluded from
19 coverage under section 1977A(a)(1) of the Revised
20 Statutes).

21 (e) *EMPLOYEES COVERED BY SECTION 717 OF THE*
22 *CIVIL RIGHTS ACT OF 1964.*—

23 (1) *IN GENERAL.*—The powers, remedies, and
24 procedures provided in section 717 of the Civil Rights
25 Act of 1964 (42 U.S.C. 2000e–16) to the Commission,

1 *the Attorney General, the Librarian of Congress, or*
2 *any person, alleging a violation of that section shall*
3 *be the powers, remedies, and procedures this title pro-*
4 *vides to the Commission, the Attorney General, the*
5 *Librarian of Congress, or any person, respectively, al-*
6 *leging an unlawful employment practice in violation*
7 *of this title against an employee or applicant de-*
8 *scribed in section 201(2)(A)(v), except as provided in*
9 *paragraphs (2) and (3).*

10 (2) *COSTS AND FEES.—The powers, remedies,*
11 *and procedures provided in subsections (b) and (c) of*
12 *section 722 of the Revised Statutes (42 U.S.C. 1988),*
13 *shall be powers, remedies, and procedures this title*
14 *provides to the Commission, the Attorney General, the*
15 *Librarian of Congress, or any person, alleging such a*
16 *practice.*

17 (3) *DAMAGES.—The powers, remedies, and pro-*
18 *cedures provided in section 1977A of the Revised*
19 *Statutes (42 U.S.C. 1981a), including the limitations*
20 *contained in subsection (b)(3) of such section 1977A,*
21 *shall be powers, remedies, and procedures this title*
22 *provides to the Commission, the Attorney General, the*
23 *Librarian of Congress, or any person, alleging such a*
24 *practice (not an employment practice specifically ex-*

1 *cluded from coverage under section 1977A(a)(1) of the*
 2 *Revised Statutes).*

3 (f) *DEFINITION.—In this section, the term “Commis-*
 4 *sion” means the Equal Employment Opportunity Commis-*
 5 *sion.*

6 **SEC. 208. DISPARATE IMPACT.**

7 (a) *GENERAL RULE.—Notwithstanding any other pro-*
 8 *vision of this Act, “disparate impact”, as that term is used*
 9 *in section 703(k) of the Civil Rights Act of 1964 (42 U.S.C.*
 10 *2000e–d(k))), on the basis of genetic information does not*
 11 *establish a cause of action under this Act.*

12 (b) *COMMISSION.—On the date that is 6 years after*
 13 *the date of enactment of this Act, there shall be established*
 14 *a commission, to be known as the Genetic Nondiscrimina-*
 15 *tion Study Commission (referred to in this section as the*
 16 *“Commission”) to review the developing science of genetics*
 17 *and to make recommendations to Congress regarding wheth-*
 18 *er to provide a disparate impact cause of action under this*
 19 *Act.*

20 (c) *MEMBERSHIP.—*

21 (1) *IN GENERAL.—The Commission shall be com-*
 22 *posed of 8 members, of which—*

23 (A) *1 member shall be appointed by the Ma-*
 24 *jority Leader of the Senate;*

1 (B) 1 member shall be appointed by the Mi-
2 nority Leader of the Senate;

3 (C) 1 member shall be appointed by the
4 Chairman of the Committee on Health, Edu-
5 cation, Labor, and Pensions of the Senate;

6 (D) 1 member shall be appointed by the
7 ranking minority member of the Committee on
8 Health, Education, Labor, and Pensions of the
9 Senate;

10 (E) 1 member shall be appointed by the
11 Speaker of the House of Representative;

12 (F) 1 member shall be appointed by the Mi-
13 nority Leader of the House of Representative;

14 (G) 1 member shall be appointed by the
15 Chairman of the Committee on Education and
16 the Workforce of the House of Representatives;
17 and

18 (H) 1 member shall be appointed by the
19 ranking minority member of the Committee on
20 Education and the Workforce of the House of
21 Representatives.

22 (2) COMPENSATION AND EXPENSES.—The mem-
23 bers of the Commission shall not receive compensation
24 for the performance of services for the Commission,
25 but shall be allowed travel expenses, including per

1 *diem in lieu of subsistence, at rates authorized for*
2 *employees of agencies under subchapter I of chapter*
3 *57 of title 5, United States Code, while away from*
4 *their homes or regular places of business in the per-*
5 *formance of services for the Commission.*

6 (d) *ADMINISTRATIVE PROVISIONS.—*

7 (1) *LOCATION.—The Commission shall be located*
8 *in a facility maintained by the Equal Employment*
9 *Opportunity Commission.*

10 (2) *DETAIL OF GOVERNMENT EMPLOYEES.—Any*
11 *Federal Government employee may be detailed to the*
12 *Commission without reimbursement, and such detail*
13 *shall be without interruption or loss of civil service*
14 *status or privilege.*

15 (3) *INFORMATION FROM FEDERAL AGENCIES.—*
16 *The Commission may secure directly from any Fed-*
17 *eral department or agency such information as the*
18 *Commission considers necessary to carry out the pro-*
19 *visions of this section. Upon request of the Commis-*
20 *sion, the head of such department or agency shall fur-*
21 *nish such information to the Commission.*

22 (4) *HEARINGS.—The Commission may hold such*
23 *hearings, sit and act at such times and places, take*
24 *such testimony, and receive such evidence as the Com-*
25 *mission considers advisable to carry out the objectives*

1 of this section, except that, to the extent possible, the
2 Commission shall use existing data and research.

3 (5) *POSTAL SERVICES.*—The Commission may
4 use the United States mails in the same manner and
5 under the same conditions as other departments and
6 agencies of the Federal Government.

7 (e) *REPORT.*—Not later than 1 year after all of the
8 members are appointed to the Commission under subsection
9 (c)(1), the Commission shall submit to Congress a report
10 that summarizes the findings of the Commission and makes
11 such recommendations for legislation as are consistent with
12 this Act.

13 (f) *AUTHORIZATION OF APPROPRIATIONS.*—There are
14 authorized to be appropriated to the Equal Employment
15 Opportunity Commission such sums as may be necessary
16 to carry out this section.

17 **SEC. 209. CONSTRUCTION.**

18 Nothing in this title shall be construed to—

19 (1) limit the rights or protections of an indi-
20 vidual under the Americans with Disabilities Act of
21 1990 (42 U.S.C. 12101 et seq.), including coverage af-
22 forded to individuals under section 102 of such Act
23 (42 U.S.C. 12112), or under the Rehabilitation Act of
24 1973 (29 U.S.C. 701 et seq.);

1 (2)(A) *limit the rights or protections of an indi-*
2 *vidual to bring an action under this title against an*
3 *employer, employment agency, labor organization, or*
4 *joint labor-management committee for a violation of*
5 *this title; or*

6 (B) *establish a violation under this title for an*
7 *employer, employment agency, labor organization, or*
8 *joint labor-management committee of a provision of*
9 *the amendments made by title I;*

10 (3) *limit the rights or protections of an indi-*
11 *vidual under any other Federal or State statute that*
12 *provides equal or greater protection to an individual*
13 *than the rights or protections provided for under this*
14 *title;*

15 (4) *apply to the Armed Forces Repository of*
16 *Specimen Samples for the Identification of Remains;*

17 (5) *limit or expand the protections, rights, or ob-*
18 *ligations of employees or employers under applicable*
19 *workers' compensation laws;*

20 (6) *limit the authority of a Federal department*
21 *or agency to conduct or sponsor occupational or other*
22 *health research that is conducted in compliance with*
23 *the regulations contained in part 46 of title 45, Code*
24 *of Federal Regulations (or any corresponding or simi-*
25 *lar regulation or rule); and*

1 (7) *limit the statutory or regulatory authority of*
2 *the Occupational Safety and Health Administration*
3 *or the Mine Safety and Health Administration to*
4 *promulgate or enforce workplace safety and health*
5 *laws and regulations.*

6 **SEC. 210. MEDICAL INFORMATION THAT IS NOT GENETIC**
7 **INFORMATION.**

8 *An employer, employment agency, labor organization,*
9 *or joint labor-management committee shall not be consid-*
10 *ered to be in violation of this title based on the use, acquisi-*
11 *tion, or disclosure of medical information that is not genetic*
12 *information about a manifested disease, disorder, or patho-*
13 *logical condition of an employee or member, including a*
14 *manifested disease, disorder, or pathological condition that*
15 *has or may have a genetic basis.*

16 **SEC. 211. REGULATIONS.**

17 *Not later than 1 year after the date of enactment of*
18 *this title, the Commission shall issue final regulations in*
19 *an accessible format to carry out this title.*

20 **SEC. 212. AUTHORIZATION OF APPROPRIATIONS.**

21 *There are authorized to be appropriated such sums as*
22 *may be necessary to carry out this title (except for section*
23 *208).*

1 **SEC. 213. EFFECTIVE DATE.**

2 *This title takes effect on the date that is 18 months*
3 *after the date of enactment of this Act.*

4 **TITLE III—MISCELLANEOUS**
5 **PROVISION**

6 **SEC. 301. SEVERABILITY.**

7 *If any provision of this Act, an amendment made by*
8 *this Act, or the application of such provision or amendment*
9 *to any person or circumstance is held to be unconstitu-*
10 *tional, the remainder of this Act, the amendments made by*
11 *this Act, and the application of such provisions to any per-*
12 *son or circumstance shall not be affected thereby.*

Calendar No. 247

108TH CONGRESS
1ST SESSION

S. 1053

[Report No. 108-122]

A BILL

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

JULY 31 (legislative day, JULY 21), 2003

Reported with an amendment