

108TH CONGRESS
1ST SESSION

S. 1053

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. JEFFORDS, Mr. ENZI, Ms. COLLINS, Mr. HAGEL, Mr. DEWINE, and Mr. GREGG) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To prohibit discrimination on the basis of genetic information with respect to health insurance 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(c) 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 including 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 (c) DEFINITIONS.—Section 733(d) of the Employee
2 Retirement Income Security Act of 1974 (29 U.S.C.
3 1191b(d)) is amended by adding at the end the following:

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

6 “(A) the spouse of the individual;

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

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

13 “(6) GENETIC INFORMATION.—

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 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 regu-
2 lations 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
3 is 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 (e) 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 cessible 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 volved 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 (c) LIMITATION AND EXCEPTION.—Subsections (c)
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 (e) 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 employer, 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.

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