

108TH CONGRESS
1ST SESSION

S. 1053

AN ACT

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; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Genetic Information Nondiscrimination Act of 2003”.

1 (b) TABLE OF CONTENTS.—The table of contents of
 2 this Act is as follows:

Sec. 1. Short title; table of contents.
 Sec. 2. Findings.

TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE

Sec. 101. Amendments to Employee Retirement Income Security Act of 1974.
 Sec. 102. Amendments to the Public Health Service Act.
 Sec. 103. Amendments to the Internal Revenue Code of 1986.
 Sec. 104. Amendments to title XVIII of the Social Security Act relating to
 medigap.
 Sec. 105. Privacy and confidentiality.
 Sec. 106. Assuring coordination.
 Sec. 107. Regulations; effective date.

TITLE II—PROHIBITING EMPLOYMENT DISCRIMINATION ON THE
 BASIS OF GENETIC INFORMATION

Sec. 201. Definitions.
 Sec. 202. Employer practices.
 Sec. 203. Employment agency practices.
 Sec. 204. Labor organization practices.
 Sec. 205. Training programs.
 Sec. 206. Confidentiality of genetic information.
 Sec. 207. Remedies and enforcement.
 Sec. 208. Disparate impact.
 Sec. 209. Construction.
 Sec. 210. Medical information that is not genetic information.
 Sec. 211. Regulations.
 Sec. 212. Authorization of appropriations.
 Sec. 213. Effective date.

TITLE III—MISCELLANEOUS PROVISION

Sec. 301. Severability.

3 **SEC. 2. FINDINGS.**

4 Congress makes the following findings:

5 (1) Deciphering the sequence of the human ge-
 6 nome and other advances in genetics open major
 7 new opportunities for medical progress. New knowl-
 8 edge about the genetic basis of illness will allow for
 9 earlier detection of illnesses, often before symptoms
 10 have begun. Genetic testing can allow individuals to

1 take steps to reduce the likelihood that they will con-
2 tract a particular disorder. New knowledge about ge-
3 netics may allow for the development of better thera-
4 pies that are more effective against disease or have
5 fewer side effects than current treatments. These
6 advances give rise to the potential misuse of genetic
7 information to discriminate in health insurance and
8 employment.

9 (2) The early science of genetics became the
10 basis of State laws that provided for the sterilization
11 of persons having presumed genetic “defects” such
12 as mental retardation, mental disease, epilepsy,
13 blindness, and hearing loss, among other conditions.
14 The first sterilization law was enacted in the State
15 of Indiana in 1907. By 1981, a majority of States
16 adopted sterilization laws to “correct” apparent ge-
17 netic traits or tendencies. Many of these State laws
18 have since been repealed, and many have been modi-
19 fied to include essential constitutional requirements
20 of due process and equal protection. However, the
21 current explosion in the science of genetics, and the
22 history of sterilization laws by the States based on
23 early genetic science, compels Congressional action
24 in this area.

1 (3) Although genes are facially neutral markers,
2 many genetic conditions and disorders are associated
3 with particular racial and ethnic groups and gender.
4 Because some genetic traits are most prevalent in
5 particular groups, members of a particular group
6 may be stigmatized or discriminated against as a re-
7 sult of that genetic information. This form of dis-
8 crimination was evident in the 1970s, which saw the
9 advent of programs to screen and identify carriers of
10 sickle cell anemia, a disease which afflicts African-
11 Americans. Once again, State legislatures began to
12 enact discriminatory laws in the area, and in the
13 early 1970s began mandating genetic screening of
14 all African Americans for sickle cell anemia, leading
15 to discrimination and unnecessary fear. To alleviate
16 some of this stigma, Congress in 1972 passed the
17 National Sickle Cell Anemia Control Act, which
18 withholds Federal funding from States unless sickle
19 cell testing is voluntary.

20 (4) Congress has been informed of examples of
21 genetic discrimination in the workplace. These in-
22 clude the use of pre-employment genetic screening at
23 Lawrence Berkeley Laboratory, which led to a court
24 decision in favor of the employees in that case *Nor-*
25 *man-Bloodsaw v. Lawrence Berkeley Laboratory* (135

1 F.3d 1260, 1269 (9th Cir. 1998)). Congress clearly
2 has a compelling public interest in relieving the fear
3 of discrimination and in prohibiting its actual prac-
4 tice in employment and health insurance.

5 (5) Federal law addressing genetic discrimina-
6 tion in health insurance and employment is incom-
7 plete in both the scope and depth of its protections.
8 Moreover, while many States have enacted some type
9 of genetic non-discrimination law, these laws vary
10 widely with respect to their approach, application,
11 and level of protection. Congress has collected sub-
12 stantial evidence that the American public and the
13 medical community find the existing patchwork of
14 State and Federal laws to be confusing and inad-
15 equate to protect them from discrimination. There-
16 fore Federal legislation establishing a national and
17 uniform basic standard is necessary to fully protect
18 the public from discrimination and allay their con-
19 cerns about the potential for discrimination, thereby
20 allowing individuals to take advantage of genetic
21 testing, technologies, research, and new therapies.

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 services
 15 by an individual or family member of such indi-
 16 vidual)”.

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

21 (A) in paragraph (2)(A), by inserting be-
 22 fore the semicolon the following: “except as pro-
 23 vided in paragraph (3)”;

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

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

12 (b) LIMITATIONS ON GENETIC TESTING.—Section
13 702 of the Employee Retirement Income Security Act of
14 1974 (29 U.S.C. 1182) is amended by adding at the end
15 the following:

16 “(c) GENETIC TESTING.—

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

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

1 “(A) limit the authority of a health care
2 professional who is providing health care serv-
3 ices with respect to an individual to request
4 that such individual or a family member of such
5 individual undergo a genetic test;

6 “(B) limit the authority of a health care
7 professional who is employed by or affiliated
8 with a group health plan or a health insurance
9 issuer and who is providing health care services
10 to an individual as part of a bona fide wellness
11 program to notify such individual of the avail-
12 ability of a genetic test or to provide informa-
13 tion to such individual regarding such genetic
14 test; or

15 “(C) authorize or permit a health care pro-
16 fessional to require that an individual undergo
17 a genetic test.

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

22 (c) REMEDIES AND ENFORCEMENT.—Section 502 of
23 the Employee Retirement Income Security Act of 1974
24 (29 U.S.C. 1132) is amended by adding at the end the
25 following:

1 “(n) ENFORCEMENT OF GENETIC NONDISCRIMINA-
2 TION REQUIREMENTS.—

3 “(1) INJUNCTIVE RELIEF FOR IRREPARABLE
4 HARM.—With respect to any violation of subsection
5 (a)(1)(F), (b)(3), or (c) of section 702, a participant
6 or beneficiary may seek relief under subsection
7 502(a)(1)(B) prior to the exhaustion of available ad-
8 ministrative remedies under section 503 if it is dem-
9 onstrated to the court, by a preponderance of the
10 evidence, that the exhaustion of such remedies would
11 cause irreparable harm to the health of the partici-
12 pant or beneficiary. Any determinations that already
13 have been made under section 503 in such case, or
14 that are made in such case while an action under
15 this paragraph is pending, shall be given due consid-
16 eration by the court in any action under this sub-
17 section in such case.

18 “(2) EQUITABLE RELIEF FOR GENETIC NON-
19 DISCRIMINATION.—

20 “(A) REINSTATEMENT OF BENEFITS
21 WHERE EQUITABLE RELIEF HAS BEEN AWARD-
22 ED.—The recovery of benefits by a participant
23 or beneficiary under a civil action under this
24 section may include an administrative penalty
25 under subparagraph (B) and the retroactive re-

1 instatement of coverage under the plan involved
2 to the date on which the participant or bene-
3 ficiary was denied eligibility for coverage if—

4 “(i) the civil action was commenced
5 under subsection (a)(1)(B); and

6 “(ii) the denial of coverage on which
7 such civil action was based constitutes a
8 violation of subsection (a)(1)(F), (b)(3), or
9 (c) of section 702.

10 “(B) ADMINISTRATIVE PENALTY.—

11 “(i) IN GENERAL.—An administrator
12 who fails to comply with the requirements
13 of subsection (a)(1)(F), (b)(3), or (c) of
14 section 702 with respect to a participant or
15 beneficiary may, in an action commenced
16 under subsection (a)(1)(B), be personally
17 liable in the discretion of the court, for a
18 penalty in the amount not more than \$100
19 for each day in the noncompliance period.

20 “(ii) NONCOMPLIANCE PERIOD.—For
21 purposes of clause (i), the term ‘non-
22 compliance period’ means the period—

23 “(I) beginning on the date that a
24 failure described in clause (i) occurs;
25 and

1 “(II) ending on the date that
2 such failure is corrected.

3 “(iii) PAYMENT TO PARTICIPANT OR
4 BENEFICIARY.—A penalty collected under
5 this subparagraph shall be paid to the par-
6 ticipant or beneficiary involved.

7 “(3) SECRETARIAL ENFORCEMENT AUTHOR-
8 ITY.—

9 “(A) GENERAL RULE.—The Secretary has
10 the authority to impose a penalty on any failure
11 of a group health plan to meet the requirements
12 of subsection (a)(1)(F), (b)(3), or (c) of section
13 702.

14 “(B) AMOUNT.—

15 “(i) IN GENERAL.—The amount of
16 the penalty imposed by subparagraph (A)
17 shall be \$100 for each day in the non-
18 compliance period with respect to each in-
19 dividual to whom such failure relates.

20 “(ii) NONCOMPLIANCE PERIOD.—For
21 purposes of this paragraph, the term ‘non-
22 compliance period’ means, with respect to
23 any failure, the period—

24 “(I) beginning on the date such
25 failure first occurs; and

1 “(II) ending on the date such
2 failure is corrected.

3 “(C) MINIMUM PENALTIES WHERE FAIL-
4 URE DISCOVERED.—Notwithstanding clauses (i)
5 and (ii) of subparagraph (D):

6 “(i) IN GENERAL.—In the case of 1 or
7 more failures with respect to an
8 individual—

9 “(I) which are not corrected be-
10 fore the date on which the plan re-
11 ceives a notice from the Secretary of
12 such violation; and

13 “(II) which occurred or continued
14 during the period involved;
15 the amount of penalty imposed by subpara-
16 graph (A) by reason of such failures with
17 respect to such individual shall not be less
18 than \$2,500.

19 “(ii) HIGHER MINIMUM PENALTY
20 WHERE VIOLATIONS ARE MORE THAN DE
21 MINIMIS.—To the extent violations for
22 which any person is liable under this para-
23 graph for any year are more than de mini-
24 mis, clause (i) shall be applied by sub-

1 stituting ‘\$15,000’ for ‘\$2,500’ with re-
2 spect to such person.

3 “(D) LIMITATIONS.—

4 “ (i) PENALTY NOT TO APPLY WHERE
5 FAILURE NOT DISCOVERED EXERCISING
6 REASONABLE DILIGENCE.—No penalty
7 shall be imposed by subparagraph (A) on
8 any failure during any period for which it
9 is established to the satisfaction of the
10 Secretary that the person otherwise liable
11 for such penalty did not know, and exer-
12 cising reasonable diligence would not have
13 known, that such failure existed.

14 “(ii) PENALTY NOT TO APPLY TO
15 FAILURES CORRECTED WITHIN CERTAIN
16 PERIODS.—No penalty shall be imposed by
17 subparagraph (A) on any failure if—

18 “(I) such failure was due to rea-
19 sonable cause and not to willful ne-
20 glect; and

21 “(II) such failure is corrected
22 during the 30-day period beginning on
23 the first date the person otherwise lia-
24 ble for such penalty knew, or exer-

1 cising reasonable diligence would have
2 known, that such failure existed.

3 “(iii) OVERALL LIMITATION FOR UN-
4 INTENTIONAL FAILURES.—In the case of
5 failures which are due to reasonable cause
6 and not to willful neglect, the penalty im-
7 posed by subparagraph (A) for failures
8 shall not exceed the amount equal to the
9 lesser of—

10 “(I) 10 percent of the aggregate
11 amount paid or incurred by the em-
12 ployer (or predecessor employer) dur-
13 ing the preceding taxable year for
14 group health plans; or

15 “(II) \$500,000.

16 “(E) WAIVER BY SECRETARY.—In the case
17 of a failure which is due to reasonable cause
18 and not to willful neglect, the Secretary may
19 waive part or all of the penalty imposed by sub-
20 paragraph (A) to the extent that the payment
21 of such penalty would be excessive relative to
22 the failure involved.”.

23 (d) DEFINITIONS.—Section 733(d) of the Employee
24 Retirement Income Security Act of 1974 (29 U.S.C.
25 1191b(d)) is amended by adding at the end the following:

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

3 “(A) the spouse of the individual;

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

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

10 “(6) GENETIC INFORMATION.—

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 mem-
16 bers of the individual; or

17 “(iii) the occurrence of a disease or
18 disorder in family members of the indi-
19 vidual.

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

23 “(7) GENETIC TEST.—

24 “(A) IN GENERAL.—The term ‘genetic
25 test’ means an analysis of human DNA, RNA,

1 chromosomes, proteins, or metabolites, that de-
2 tects genotypes, mutations, or chromosomal
3 changes.

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

6 “(i) an analysis of proteins or metabo-
7 lites that does not detect genotypes,
8 mutations, or chromosomal changes; or

9 “(ii) an analysis of proteins or me-
10 tabolites that is directly related to a mani-
11 fested disease, disorder, or pathological
12 condition that could reasonably be detected
13 by a health care professional with appro-
14 priate training and expertise in the field of
15 medicine involved.

16 “(8) GENETIC SERVICES.—The term ‘genetic
17 services’ means—

18 “(A) a genetic test;

19 “(B) genetic counseling (such as obtaining,
20 interpreting, or assessing genetic information);

21 or

22 “(C) genetic education.”

23 (e) REGULATIONS AND EFFECTIVE DATE.—

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

1 Labor shall issue final regulations in an accessible
 2 format to carry out the amendments made by this
 3 section.

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

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

10 **ACT.**

11 (a) AMENDMENTS RELATING TO THE GROUP MAR-
 12 KET.—

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

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

24 (B) NO DISCRIMINATION IN GROUP PRE-
 25 MIUMS BASED ON GENETIC INFORMATION.—

1 Section 2702(b) of the Public Health Service
2 Act (42 U.S.C. 300gg-1(b)) is amended—

3 (i) in paragraph (2)(A), by inserting
4 before the semicolon the following: “, ex-
5 cept as provided in paragraph (3)”;

6 (ii) by adding at the end the fol-
7 lowing:

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

19 (2) LIMITATIONS ON GENETIC TESTING.—Sec-
20 tion 2702 of the Public Health Service Act (42
21 U.S.C. 300gg-1) is amended by adding at the end
22 the following:

23 “(c) GENETIC TESTING.—

24 “(1) LIMITATION ON REQUESTING OR REQUIR-
25 ING GENETIC TESTING.—A group health plan, or a

1 health insurance issuer offering health insurance
2 coverage in connection with a group health plan,
3 shall not request or require an individual or a family
4 member of such individual to undergo a genetic test.

5 “(2) RULE OF CONSTRUCTION.—Nothing in
6 this part shall be construed to—

7 “(A) limit the authority of a health care
8 professional who is providing health care serv-
9 ices with respect to an individual to request
10 that such individual or a family member of such
11 individual undergo a genetic test;

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

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

24 “(d) APPLICATION TO ALL PLANS.—The provisions
25 of subsections (a)(1)(F), (b)(3), and (c) shall apply to

1 group health plans and health insurance issuers without
2 regard to section 2721(a).”.

3 (3) REMEDIES AND ENFORCEMENT.—Section
4 2722(b) of the Public Health Service Act (42 U.S.C.
5 300gg-22)(b)) is amended by adding at the end the
6 following:

7 “(3) ENFORCEMENT AUTHORITY RELATING TO
8 GENETIC DISCRIMINATION.—

9 “(A) GENERAL RULE.—In the cases de-
10 scribed in paragraph (1), notwithstanding the
11 provisions of paragraph (2)(C), the following
12 provisions shall apply with respect to an action
13 under this subsection by the Secretary with re-
14 spect to any failure of a health insurance issuer
15 in connection with a group health plan, to meet
16 the requirements of subsection (a)(1)(F),
17 (b)(3), or (c) of section 2702.

18 “(B) AMOUNT.—

19 “(i) IN GENERAL.—The amount of
20 the penalty imposed under this paragraph
21 shall be \$100 for each day in the non-
22 compliance period with respect to each in-
23 dividual to whom such failure relates.

24 “(ii) NONCOMPLIANCE PERIOD.—For
25 purposes of this paragraph, the term ‘non-

1 compliance period' means, with respect to
2 any failure, the period—

3 “(I) beginning on the date such
4 failure first occurs; and

5 “(II) ending on the date such
6 failure is corrected.

7 “(C) MINIMUM PENALTIES WHERE FAIL-
8 URE DISCOVERED.—Notwithstanding clauses (i)
9 and (ii) of subparagraph (D):

10 “(i) IN GENERAL.—In the case of 1 or
11 more failures with respect to an
12 individual—

13 “(I) which are not corrected be-
14 fore the date on which the plan re-
15 ceives a notice from the Secretary of
16 such violation; and

17 “(II) which occurred or continued
18 during the period involved;

19 the amount of penalty imposed by subpara-
20 graph (A) by reason of such failures with
21 respect to such individual shall not be less
22 than \$2,500.

23 “(ii) HIGHER MINIMUM PENALTY
24 WHERE VIOLATIONS ARE MORE THAN DE
25 MINIMIS.—To the extent violations for

1 which any person is liable under this para-
2 graph for any year are more than de mini-
3 mis, clause (i) shall be applied by sub-
4 stituting ‘\$15,000’ for ‘\$2,500’ with re-
5 spect to such person.

6 “(D) LIMITATIONS.—

7 “(i) PENALTY NOT TO APPLY WHERE
8 FAILURE NOT DISCOVERED EXERCISING
9 REASONABLE DILIGENCE.—No penalty
10 shall be imposed by subparagraph (A) on
11 any failure during any period for which it
12 is established to the satisfaction of the
13 Secretary that the person otherwise liable
14 for such penalty did not know, and exer-
15 cising reasonable diligence would not have
16 known, that such failure existed.

17 “(ii) PENALTY NOT TO APPLY TO FAIL-
18 URES CORRECTED WITHIN CERTAIN PERI-
19 ODS.—No penalty shall be imposed by sub-
20 paragraph (A) on any failure if—

21 “(I) such failure was due to rea-
22 sonable cause and not to willful ne-
23 glect; and

24 “(II) such failure is corrected
25 during the 30-day period beginning on

1 the first date the person otherwise lia-
2 ble for such penalty knew, or exer-
3 cising reasonable diligence would have
4 known, that such failure existed.

5 “(iii) OVERALL LIMITATION FOR UN-
6 INTENTIONAL FAILURES.—In the case of
7 failures which are due to reasonable cause
8 and not to willful neglect, the penalty im-
9 posed by subparagraph (A) for failures
10 shall not exceed the amount equal to the
11 lesser of—

12 “(I) 10 percent of the aggregate
13 amount paid or incurred by the em-
14 ployer (or predecessor employer) dur-
15 ing the preceding taxable year for
16 group health plans; or

17 “(II) \$500,000.

18 “(E) WAIVER BY SECRETARY.—In the case
19 of a failure which is due to reasonable cause
20 and not to willful neglect, the Secretary may
21 waive part or all of the penalty imposed by sub-
22 paragraph (A) to the extent that the payment
23 of such penalty would be excessive relative to
24 the failure involved.”.

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

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

6 “(A) the spouse of the individual;

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

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

13 “(16) GENETIC INFORMATION.—

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

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

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

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

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

1 “(17) GENETIC TEST.—

2 “(A) IN GENERAL.—The term ‘genetic
3 test’ means an analysis of human DNA, RNA,
4 chromosomes, proteins, or metabolites, that de-
5 tects genotypes, mutations, or chromosomal
6 changes.

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

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

12 “(ii) an analysis of proteins or me-
13 tabolites that is directly related to a mani-
14 fested disease, disorder, or pathological
15 condition that could reasonably be detected
16 by a health care professional with appro-
17 priate training and expertise in the field of
18 medicine involved.

19 “(18) GENETIC SERVICES.—The term ‘genetic
20 services’ means—

21 “(A) a genetic test;

22 “(B) genetic counseling (such as obtaining,
23 interpreting, or assessing genetic information);

24 or

25 “(C) genetic education.”.

1 (b) AMENDMENT RELATING TO THE INDIVIDUAL
2 MARKET.—

3 (1) IN GENERAL.—The first subpart 3 of part
4 B of title XXVII of the Public Health Service Act
5 (42 U.S.C. 300gg–51 et seq.) (relating to other re-
6 quirements) is amended—

7 (A) by redesignating such subpart as sub-
8 part 2; and

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

10 **“SEC. 2753. PROHIBITION OF HEALTH DISCRIMINATION ON**
11 **THE BASIS OF GENETIC INFORMATION.**

12 “(a) PROHIBITION ON GENETIC INFORMATION AS A
13 CONDITION OF ELIGIBILITY.—A health insurance issuer
14 offering health insurance coverage in the individual mar-
15 ket may not establish rules for the eligibility (including
16 continued eligibility) of any individual to enroll in indi-
17 vidual health insurance coverage based on genetic infor-
18 mation (including information about a request for or re-
19 ceipt of genetic services by an individual or family member
20 of such individual).

21 “(b) PROHIBITION ON GENETIC INFORMATION IN
22 SETTING PREMIUM RATES.—A health insurance issuer of-
23 fering health insurance coverage in the individual market
24 shall not adjust premium or contribution amounts for an
25 individual on the basis of genetic information concerning

1 the individual or a family member of the individual (in-
2 cluding information about a request for or receipt of ge-
3 netic services by an individual or family member of such
4 individual).

5 “(c) GENETIC TESTING.—

6 “(1) LIMITATION ON REQUESTING OR REQUIR-
7 ING GENETIC TESTING.—A health insurance issuer
8 offering health insurance coverage in the individual
9 market shall not request or require an individual or
10 a family member of such individual to undergo a ge-
11 netic test.

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

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

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

1 test or to provide information to such individual
2 regarding such genetic test; or

3 “(C) authorize or permit a health care pro-
4 fessional to require that an individual undergo
5 a genetic test.”.

6 (2) REMEDIES AND ENFORCEMENT.—Section
7 2761(b) of the Public Health Service Act (42 U.S.C.
8 300gg–61)(b)) is amended to read as follows:

9 “(b) SECRETARIAL ENFORCEMENT AUTHORITY.—
10 The Secretary shall have the same authority in relation
11 to enforcement of the provisions of this part with respect
12 to issuers of health insurance coverage in the individual
13 market in a State as the Secretary has under section
14 2722(b)(2), and section 2722(b)(3) with respect to viola-
15 tions of genetic nondiscrimination provisions, in relation
16 to the enforcement of the provisions of part A with respect
17 to issuers of health insurance coverage in the small group
18 market in the State.”.

19 (c) ELIMINATION OF OPTION OF NON-FEDERAL
20 GOVERNMENTAL PLANS TO BE EXCEPTED FROM RE-
21 QUIREMENTS CONCERNING GENETIC INFORMATION.—
22 Section 2721(b)(2) of the Public Health Service Act (42
23 U.S. C. 300gg–21(b)(2)) is amended—

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

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

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

16 (d) REGULATIONS AND EFFECTIVE DATE.—

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

23 (2) EFFECTIVE DATE.—The amendments made
24 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
 10 of 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
 15 SERVICES.—

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

23 (2) NO DISCRIMINATION IN GROUP PREMIUMS
 24 BASED ON GENETIC INFORMATION.—Section

1 9802(b) of the Internal Revenue Code of 1986 is
2 amended—

3 (A) in paragraph (2)(A), by inserting be-
4 fore the semicolon the following: “, except as
5 provided in paragraph (3)”;

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

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

16 (b) LIMITATIONS ON GENETIC TESTING.—Section
17 9802 of the Internal Revenue Code of 1986 is amended
18 by adding at the end the following:

19 “(d) GENETIC TESTING AND GENETIC SERVICES.—

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

24 “(2) RULE OF CONSTRUCTION.—Nothing in
25 this part shall be construed to—

1 “(A) limit the authority of a health care
2 professional who is providing health care serv-
3 ices with respect to an individual to request
4 that such individual or a family member of such
5 individual undergo a genetic test;

6 “(B) limit the authority of a health care
7 professional who is employed by or affiliated
8 with a group health plan and who is providing
9 health care services to an individual as part of
10 a bona fide wellness program to notify such in-
11 dividual of the availability of a genetic test or
12 to provide information to such individual re-
13 garding such genetic test; or

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

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

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

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

1 “(A) the spouse of the individual;

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

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

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

10 “(A) a genetic test;

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

14 “(C) genetic education.

15 “(8) GENETIC INFORMATION.—

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

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

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

22 “(iii) the occurrence of a disease or
23 disorder in family members of the indi-
24 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
6 test’ means an analysis of human DNA, RNA,
7 chromosomes, proteins, or metabolites, that de-
8 tects genotypes, mutations, or chromosomal
9 changes.

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

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

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

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. 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
12 Social Security Act (42 U.S.C. 1395ss(s)(2)) is
13 amended 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, ge-
22 netic services by such individual or family mem-
23 ber of 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
 4 by paragraph (1) shall apply with respect to a policy
 5 for 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
 9 Security Act (42 U.S.C. 1395ss) is amended by add-
 10 ing 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
 19 in 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 sup-
4 plemental policy and who is providing
5 health care services to an individual as
6 part of a bona fide wellness program to no-
7 tify such individual of the availability of a
8 genetic test or to provide information to
9 such individual regarding such genetic test;
10 or

11 “(iii) authorize or permit a health
12 care professional to require that an indi-
13 vidual undergo a genetic test.

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

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

17 “(i) the spouse of the individual;

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

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

24 “(B) GENETIC INFORMATION.—

1 “(i) IN GENERAL.—Except as pro-
2 vided in clause (ii), the term ‘genetic infor-
3 mation’ 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 metabo-
17 lites, that detects genotypes, mutations, or
18 chromosomal 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
3 a manifested disease, disorder, or
4 pathological condition that could rea-
5 sonably be detected by a health care
6 professional with appropriate training
7 and expertise in the field of medicine
8 involved.

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 medi-
18 care supplemental policy’ includes a third-party
19 administrator or other person acting for or on
20 behalf of such issuer.”.

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

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
8 months after the date of enactment of this Act.

9 (c) TRANSITION PROVISIONS.—

10 (1) IN GENERAL.—If the Secretary of Health
11 and Human Services identifies a State as requiring
12 a 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 require-
16 ments of section 1882 of the Social Security Act due
17 solely to failure to make such change until the date
18 specified in paragraph (4).

19 (2) NAIC STANDARDS.—If, not later than June
20 30, 2004, the National Association of Insurance
21 Commissioners (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 regula-
4 tion (including the revised NAIC model regulation
5 and the 1991 NAIC Model Regulation) for the pur-
6 poses of such section.

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

16 (4) DATE SPECIFIED.—

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

20 (i) the date the State changes its stat-
21 utes or regulations to conform its regu-
22 latory program to the changes made by
23 this section, 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
19 deemed to be a separate regular session of the
20 State legislature.

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

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

1 health coverage), and issuers of medicare supplemental
2 policies, without regard 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 Serv-
6 ice 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 INFORMA-
11 TION.—

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

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

1 individual) for purposes of underwriting, determina-
2 tions of eligibility to enroll, premium rating, or the
3 creation, renewal or replacement of a plan, contract
4 or coverage for health insurance or health benefits.

5 (c) PROHIBITION ON COLLECTION OF GENETIC IN-
6 FORMATION.—

7 (1) IN GENERAL.—A group health plan, health
8 insurance issuer, or issuer of a medicare supple-
9 mental policy shall not request, require, or purchase
10 genetic information (including information about a
11 request for or a receipt of genetic services by an in-
12 dividual or family member of such individual) for
13 purposes of underwriting, determinations of eligi-
14 bility to enroll, premium rating, or the creation, re-
15 newal or replacement of a plan, contract or coverage
16 for health insurance or health benefits.

17 (2) LIMITATION RELATING TO THE COLLEC-
18 TION OF GENETIC INFORMATION PRIOR TO ENROLL-
19 MENT.—A group health plan, health insurance
20 issuer, or issuer of a medicare supplemental policy
21 shall not request, require, or purchase genetic infor-
22 mation (including information about a request for or
23 a receipt of genetic services by an individual or fam-
24 ily member of such individual) concerning a partici-
25 pant, beneficiary, or enrollee prior to the enrollment,

1 and in connection with such enrollment, of such indi-
2 vidual 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 partic-
8 ipant, 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 sub-
17 section (b).

18 (d) APPLICATION OF CONFIDENTIALITY STAND-
19 ARDS.—The provisions of subsections (b) and (c) shall not
20 apply—

21 (1) to group health plans, health insurance
22 issuers, or issuers of medicare supplemental policies
23 that are not otherwise covered under the regulations
24 promulgated by the Secretary of Health and Human
25 Services under part C of title XI of the Social Secu-

1 rity Act (42 U.S.C. 1320d et seq.) and section 264
2 of the Health Insurance Portability and Account-
3 ability Act of 1996 (42 U.S.C. 1320d–2 note); and
4 (2) to genetic information that is not considered
5 to be individually-identifiable health information
6 under the regulations promulgated by the Secretary
7 of Health and Human Services under part C of title
8 XI of the Social Security Act (42 U.S.C. 1320d et
9 seq.) and section 264 of the Health Insurance Port-
10 ability and Accountability Act of 1996 (42 U.S.C.
11 1320d–2 note).

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

20 (f) PREEMPTION.—

21 (1) IN GENERAL.—A provision or requirement
22 under this section or a regulation promulgated under
23 this section shall supersede any contrary provision of
24 State law unless such provision of State law imposes
25 requirements, standards, or implementation speci-

1 fications that are more stringent than the require-
2 ments, standards, or implementation specifications
3 imposed under this section or such regulations. No
4 penalty, remedy, or cause of action to enforce such
5 a State law that is more stringent shall be pre-
6 empted by this section.

7 (2) RULE OF CONSTRUCTION.—Nothing in
8 paragraph (1) shall be construed to establish a pen-
9 alty, remedy, or cause of action under State law if
10 such penalty, remedy, or cause of action is not oth-
11 erwise available under such State law.

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

21 (h) DEFINITIONS.—In this section:

22 (1) GENETIC INFORMATION; GENETIC SERV-
23 ICES.—The terms “family member”, “genetic infor-
24 mation”, “genetic services”, and “genetic test” have
25 the meanings given such terms in section 2791 of

1 the Public Health Service Act (42 U.S.C. 300gg–
2 91), as amended by this Act.

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

8 (3) ISSUER OF A MEDICARE SUPPLEMENTAL
9 POLICY.—The term “issuer of a medicare supple-
10 mental policy” means an issuer described in section
11 1882 of the Social Security Act (42 insert 1395ss).

12 (4) SECRETARY.—The term “Secretary” means
13 the Secretary of Health and Human Services.

14 **SEC. 106. ASSURING COORDINATION.**

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

20 (1) regulations, rulings, and interpretations
21 issued by such Secretaries relating to the same mat-
22 ter over which two or more such Secretaries have re-
23 sponsibility under this title (and the amendments
24 made by this title) are administered so as to have
25 the same effect at all times; and

1 (2) coordination of policies relating to enforcing
 2 the same requirements through such Secretaries in
 3 order to have a coordinated enforcement strategy
 4 that avoids duplication of enforcement efforts and
 5 assigns priorities in enforcement.

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

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

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

15 (b) **EFFECTIVE DATE.**—Except as provided in sec-
 16 tion 104, the amendments made by this title shall take
 17 effect on the date that is 18 months after the date of en-
 18 actment of this Act.

19 **TITLE II—PROHIBITING EM-**
 20 **PLOYMENT DISCRIMINATION**
 21 **ON THE BASIS OF GENETIC**
 22 **INFORMATION**

23 **SEC. 201. DEFINITIONS.**

24 In this title:

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

5 (2) EMPLOYEE; EMPLOYER; EMPLOYMENT
6 AGENCY; LABOR ORGANIZATION; MEMBER.—

7 (A) IN GENERAL.—The term “employee”
8 means—

9 (i) an employee (including an appli-
10 cant), as defined in section 701(f) of the
11 Civil Rights Act of 1964 (42 U.S.C.
12 2000e(f));

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

17 (iii) a covered employee (including an
18 applicant), as defined in section 101 of the
19 Congressional Accountability Act of 1995
20 (2 U.S.C. 1301);

21 (iv) a covered employee (including an
22 applicant), as defined in section 411(e) of
23 title 3, United States Code; or

1 (v) an employee or applicant to which
2 section 717(a) of the Civil Rights Act of
3 1964 (42 U.S.C. 2000e-16(a)) applies.

4 (B) EMPLOYER.—The term “employer”
5 means—

6 (i) an employer (as defined in section
7 701(b) of the Civil Rights Act of 1964 (42
8 U.S.C. 2000e(b));

9 (ii) an entity employing a State em-
10 ployee described in section 304(a) of the
11 Government Employee Rights Act of 1991;

12 (iii) an employing office, as defined in
13 section 101 of the Congressional Account-
14 ability Act of 1995;

15 (iv) an employing office, as defined in
16 section 411(c) of title 3, United States
17 Code; or

18 (v) an entity to which section 717(a)
19 of the Civil Rights Act of 1964 applies.

20 (C) EMPLOYMENT AGENCY; LABOR ORGA-
21 NIZATION.—The terms “employment agency”
22 and “labor organization” have the meanings
23 given the terms in section 701 of the Civil
24 Rights Act of 1964 (42 U.S.C. 2000e).

1 (D) MEMBER.—The term “member”, with
2 respect to a labor organization, includes an ap-
3 plicant for membership in a labor organization.

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

6 (A) the spouse of the individual;

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

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

13 (4) GENETIC INFORMATION.—

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

17 (i) an individual’s genetic tests;

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

20 (iii) the occurrence of a disease or dis-
21 order in family members of the individual.

22 (B) EXCEPTIONS.—The term “genetic in-
23 formation” shall not include information about
24 the sex or age of an individual.

1 (5) GENETIC MONITORING.—The term “genetic
2 monitoring” means the periodic examination of em-
3 ployees to evaluate acquired modifications to their
4 genetic material, such as chromosomal damage or
5 evidence of increased occurrence of mutations, that
6 may have developed in the course of employment due
7 to exposure to toxic substances in the workplace, in
8 order to identify, evaluate, and respond to the ef-
9 fects of or control adverse environmental exposures
10 in the workplace.

11 (6) GENETIC SERVICES.—The term “genetic
12 services” means—

13 (A) a genetic test;

14 (B) genetic counseling (such as obtaining,
15 interpreting or assessing genetic information);

16 or

17 (C) genetic education.

18 (7) GENETIC TEST.—

19 (A) IN GENERAL.—The term “genetic
20 test” means the analysis of human DNA, RNA,
21 chromosomes, proteins, or metabolites, that de-
22 tects genotypes, mutations, or chromosomal
23 changes.

24 (B) EXCEPTION.—The term “genetic test”
25 does not mean an analysis of proteins or me-

1 tabolites that does not detect genotypes,
2 mutations, or chromosomal changes.

3 **SEC. 202. EMPLOYER PRACTICES.**

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

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

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

23 (b) **ACQUISITION OF GENETIC INFORMATION.**—It
24 shall be an unlawful employment practice for an employer
25 to request, require, or purchase genetic information with

1 respect to an employee or a family member of the em-
2 ployee (or information about a request for the receipt of
3 genetic services by such employee or a family member of
4 such employee) except—

5 (1) where an employer inadvertently requests or
6 requires family medical history of the employee or
7 family member of the employee;

8 (2) where—

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

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

14 (C) only the employee (or family member
15 if the family member is receiving genetic serv-
16 ices) and the licensed health care professional
17 or board certified genetic counselor involved in
18 providing such services receive individually iden-
19 tifiable information concerning the results of
20 such services; and

21 (D) any individually identifiable genetic in-
22 formation provided under subparagraph (C) in
23 connection with the services provided under
24 subparagraph (A) is only available for purposes
25 of such services and shall not be disclosed to

1 the employer except in aggregate terms that do
2 not disclose the identity of specific employees;

3 (3) where an employer requests or requires
4 family medical history from the employee to comply
5 with the certification provisions of section 103 of the
6 Family and Medical Leave Act of 1993 (29 U.S.C.
7 2613) or such requirements under State family and
8 medical leave laws;

9 (4) where an employer purchases documents
10 that are commercially and publicly available (includ-
11 ing newspapers, magazines, periodicals, and books,
12 but not including medical databases or court
13 records) that include family medical history; or

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

17 (A) the employer provides written notice of
18 the genetic monitoring to the employee;

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

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

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

25 (D) the monitoring is in compliance with—

1 (i) any Federal genetic monitoring
2 regulations, 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
8 seq.), or the Atomic Energy Act of 1954
9 (42 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 employer, excluding any licensed
17 health care professional or board certified ge-
18 netic counselor that is involved in the genetic
19 monitoring program, receives the results of the
20 monitoring only in aggregate terms that do not
21 disclose the identity of specific employees;

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
25 used in violation of paragraph (1) or (2) of subsection (a)

1 or treated or disclosed in a manner that violates section
2 206.

3 **SEC. 203. EMPLOYMENT AGENCY PRACTICES.**

4 (a) USE OF GENETIC INFORMATION.—It shall be an
5 unlawful employment practice for an employment
6 agency—

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

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

22 (3) to cause or attempt to cause an employer to
23 discriminate against an individual in violation of this
24 title.

1 (b) ACQUISITION OF GENETIC INFORMATION.—It
2 shall be an unlawful employment practice for an employ-
3 ment agency to request, require, or purchase genetic infor-
4 mation with respect to an individual or a family member
5 of the individual (or information about a request for the
6 receipt of genetic services by such individual or a family
7 member of such individual) except—

8 (1) where an employment agency inadvertently
9 requests or requires family medical history of the in-
10 dividual or family member of the individual;

11 (2) where—

12 (A) health or genetic services are offered
13 by the employment agency, including such serv-
14 ices offered as part of a bona fide wellness pro-
15 gram;

16 (B) the individual provides prior, knowing,
17 voluntary, and written authorization;

18 (C) only the individual (or family member
19 if the family member is receiving genetic serv-
20 ices) and the licensed health care professional
21 or board certified genetic counselor involved in
22 providing such services receive individually iden-
23 tifiable information concerning the results of
24 such services; and

1 (D) any individually identifiable genetic in-
2 formation provided under subparagraph (C) in
3 connection with the services provided under
4 subparagraph (A) is only available for purposes
5 of such services and shall not be disclosed to
6 the employment agency except in aggregate
7 terms that do not disclose the identity of spe-
8 cific individuals;

9 (3) where an employment agency requests or re-
10 quires family medical history from the individual to
11 comply with the certification provisions of section
12 103 of the Family and Medical Leave Act of 1993
13 (29 U.S.C. 2613) or such requirements under State
14 family and medical leave laws;

15 (4) where an employment agency purchases
16 documents that are commercially and publicly avail-
17 able (including newspapers, magazines, periodicals,
18 and books, but not including medical databases or
19 court records) that include family medical history; or

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

23 (A) the employment agency provides writ-
24 ten notice of the genetic monitoring to the indi-
25 vidual;

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

3 (ii) the genetic monitoring is required by
4 Federal or State law;

5 (C) the individual is informed of individual
6 monitoring results;

7 (D) the monitoring is in compliance with—

8 (i) any Federal genetic monitoring
9 regulations, including any such regulations
10 that may be promulgated by the Secretary
11 of Labor pursuant to the Occupational
12 Safety and Health Act of 1970 (29 U.S.C.
13 651 et seq.), the Federal Mine Safety and
14 Health Act of 1977 (30 U.S.C. 801 et
15 seq.), or the Atomic Energy Act of 1954
16 (42 U.S.C. 2011 et seq.); or

17 (ii) State genetic monitoring regula-
18 tions, in the case of a State that is imple-
19 menting genetic monitoring regulations
20 under the authority of the Occupational
21 Safety and Health Act of 1970 (29 U.S.C.
22 651 et seq.); and

23 (E) the employment agency, excluding any
24 licensed health care professional or board cer-
25 tified genetic counselor that is involved in the

1 genetic monitoring program, receives the results
2 of the monitoring only in aggregate terms that
3 do not disclose the identity of specific individ-
4 uals;

5 (c) PRESERVATION OF PROTECTIONS.—In the case of
6 information to which any of paragraphs (1) through (5)
7 of subsection (b) applies, such information may not be
8 used in violation of paragraph (1) or (2) of subsection (a)
9 or treated or disclosed in a manner that violates section
10 206.

11 **SEC. 204. LABOR ORGANIZATION PRACTICES.**

12 (a) USE OF GENETIC INFORMATION.—It shall be an
13 unlawful employment practice for a labor organization—

14 (1) to exclude or to expel from the membership
15 of the organization, or otherwise to discriminate
16 against, any member because of genetic information
17 with respect to the member (or information about a
18 request for or the receipt of genetic services by such
19 member or family member of such member);

20 (2) to limit, segregate, or classify the members
21 of the organization, or fail or refuse to refer for em-
22 ployment any member, in any way that would de-
23 prive or tend to deprive any member of employment
24 opportunities, or otherwise adversely affect the sta-
25 tus of the member as an employee, because of ge-

1 netic information with respect to the member (or in-
2 formation about a request for or the receipt of ge-
3 netic services by such member or family member of
4 such member); or

5 (3) to cause or attempt to cause an employer to
6 discriminate against a member in violation of this
7 title.

8 (b) ACQUISITION OF GENETIC INFORMATION.—It
9 shall be an unlawful employment practice for a labor orga-
10 nization to request, require, or purchase genetic informa-
11 tion with respect to a member or a family member of the
12 member (or information about a request for the receipt
13 of genetic services by such member or a family member
14 of such member) except—

15 (1) where a labor organization inadvertently re-
16 quests or requires family medical history of the
17 member or family member of the member;

18 (2) where—

19 (A) health or genetic services are offered
20 by the labor organization, including such serv-
21 ices offered as part of a bona fide wellness pro-
22 gram;

23 (B) the member provides prior, knowing,
24 voluntary, and written authorization;

1 (C) only the member (or family member if
2 the family member is receiving genetic services)
3 and the licensed health care professional or
4 board certified genetic counselor involved in
5 providing such services receive individually iden-
6 tifiable information concerning the results of
7 such services; and

8 (D) any individually identifiable genetic in-
9 formation provided under subparagraph (C) in
10 connection with the services provided under
11 subparagraph (A) is only available for purposes
12 of such services and shall not be disclosed to
13 the labor organization except in aggregate
14 terms that do not disclose the identity of spe-
15 cific members;

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

22 (4) where a labor organization purchases docu-
23 ments that are commercially and publicly available
24 (including newspapers, magazines, periodicals, and

1 books, but not including medical databases or court
2 records) that include family medical history; or

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

6 (A) the labor organization provides written
7 notice of the genetic monitoring to the member;

8 (B)(i) the member provides prior, knowing,
9 voluntary, and written authorization; or

10 (ii) the genetic monitoring is required by
11 Federal or State law;

12 (C) the member is informed of individual
13 monitoring results;

14 (D) the monitoring is in compliance with—

15 (i) any Federal genetic monitoring
16 regulations, including any such regulations
17 that may be promulgated by the Secretary
18 of Labor pursuant to the Occupational
19 Safety and Health Act of 1970 (29 U.S.C.
20 651 et seq.), the Federal Mine Safety and
21 Health Act of 1977 (30 U.S.C. 801 et
22 seq.), or the Atomic Energy Act of 1954
23 (42 U.S.C. 2011 et seq.); or

24 (ii) State genetic monitoring regula-
25 tions, in the case of a State that is imple-

1 menting genetic monitoring regulations
2 under the authority of the Occupational
3 Safety and Health Act of 1970 (29 U.S.C.
4 651 et seq.); and

5 (E) the labor organization, excluding any
6 licensed health care professional or board cer-
7 tified genetic counselor that is involved in the
8 genetic monitoring program, receives the results
9 of the monitoring only in aggregate terms that
10 do not disclose the identity of specific members;

11 (c) PRESERVATION OF PROTECTIONS.—In the case of
12 information to which any of paragraphs (1) through (5)
13 of subsection (b) applies, such information may not be
14 used in violation of paragraph (1) or (2) of subsection (a)
15 or treated or disclosed in a manner that violates section
16 206.

17 **SEC. 205. TRAINING PROGRAMS.**

18 (a) USE OF GENETIC INFORMATION.—It shall be an
19 unlawful employment practice for any employer, labor or-
20 ganization, or joint labor-management committee control-
21 ling apprenticeship or other training or retraining, includ-
22 ing on-the-job training programs—

23 (1) to discriminate against any individual be-
24 cause of genetic information with respect to the indi-
25 vidual (or information about a request for or the re-

1 receipt of genetic services by such individual or a fam-
2 ily member of such individual) in admission to, or
3 employment in, any program established to provide
4 apprenticeship or other training or retraining;

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

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

20 (b) ACQUISITION OF GENETIC INFORMATION.—It
21 shall be an unlawful employment practice for an employer,
22 labor organization, or joint labor-management committee
23 described in subsection (a) to request, require, or purchase
24 genetic information with respect to an individual or a fam-
25 ily member of the individual (or information about a re-

1 quest for the receipt of genetic services by such individual
2 or a family member of such individual) except—

3 (1) where the employer, labor organization, or
4 joint labor-management committee inadvertently re-
5 quests or requires family medical history of the indi-
6 vidual or family member of the individual;

7 (2) where—

8 (A) health or genetic services are offered
9 by the employer, labor organization, or joint
10 labor-management committee, including such
11 services offered as part of a bona fide wellness
12 program;

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

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

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

1 of such services and shall not be disclosed to
2 the employer, labor organization, or joint labor-
3 management committee except in aggregate
4 terms that do not disclose the identity of spe-
5 cific individuals;

6 (3) where the employer, labor organization, or
7 joint labor-management committee requests or re-
8 quires family medical history from the individual to
9 comply with the certification provisions of section
10 103 of the Family and Medical Leave Act of 1993
11 (29 U.S.C. 2613) or such requirements under State
12 family and medical leave laws;

13 (4) where the employer, labor organization, or
14 joint labor-management committee purchases docu-
15 ments that are commercially and publicly available
16 (including newspapers, magazines, periodicals, and
17 books, but not including medical databases or court
18 records) that include family medical history; or

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

22 (A) the employer, labor organization, or
23 joint labor-management committee provides
24 written notice of the genetic monitoring to the
25 individual;

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

3 (ii) the genetic monitoring is required by
4 Federal or State law;

5 (C) the individual is informed of individual
6 monitoring results;

7 (D) the monitoring is in compliance with—

8 (i) any Federal genetic monitoring
9 regulations, including any such regulations
10 that may be promulgated by the Secretary
11 of Labor pursuant to the Occupational
12 Safety and Health Act of 1970 (29 U.S.C.
13 651 et seq.), the Federal Mine Safety and
14 Health Act of 1977 (30 U.S.C. 801 et
15 seq.), or the Atomic Energy Act of 1954
16 (42 U.S.C. 2011 et seq.); or

17 (ii) State genetic monitoring regula-
18 tions, in the case of a State that is imple-
19 menting genetic monitoring regulations
20 under the authority of the Occupational
21 Safety and Health Act of 1970 (29 U.S.C.
22 651 et seq.); and

23 (E) the employer, labor organization, or
24 joint labor-management committee, excluding
25 any licensed health care professional or board

1 certified genetic counselor that is involved in
2 the genetic monitoring program, receives the re-
3 sults of the monitoring only in aggregate terms
4 that do not disclose the identity of specific indi-
5 viduals;

6 (c) PRESERVATION OF PROTECTIONS.—In the case of
7 information to which any of paragraphs (1) through (5)
8 of subsection (b) applies, such information may not be
9 used in violation of paragraph (1) or (2) of subsection (a)
10 or treated or disclosed in a manner that violates section
11 206.

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

13 (a) TREATMENT OF INFORMATION AS PART OF CON-
14 FIDENTIAL MEDICAL RECORD.—If an employer, employ-
15 ment agency, labor organization, or joint labor-manage-
16 ment committee possesses genetic information about an
17 employee or member (or information about a request for
18 or receipt of genetic services by such employee or member
19 or family member of such employee or member), such in-
20 formation shall be maintained on separate forms and in
21 separate medical files and be treated as a confidential
22 medical record of the employee or member.

23 (b) LIMITATION ON DISCLOSURE.—An employer, em-
24 ployment agency, labor organization, or joint labor-man-
25 agement committee shall not disclose genetic information

1 concerning an employee or member (or information about
2 a request for or receipt of genetic services by such em-
3 ployee or member or family member of such employee or
4 member) except—

5 (1) to the employee (or family member if the
6 family member is receiving the genetic services) or
7 member of a labor organization at the request of the
8 employee or member of such organization;

9 (2) to an occupational or other health re-
10 searcher if the research is conducted in compliance
11 with the regulations and protections provided for
12 under part 46 of title 45, Code of Federal Regula-
13 tions;

14 (3) in response to an order of a court, except
15 that—

16 (A) the employer, employment agency,
17 labor organization, or joint labor-management
18 committee may disclose only the genetic infor-
19 mation expressly authorized by such order; and

20 (B) if the court order was secured without
21 the knowledge of the employee or member to
22 whom the information refers, the employer, em-
23 ployment agency, labor organization, or joint
24 labor-management committee shall provide the

1 employee or member with adequate notice to
2 challenge the court order;

3 (4) to government officials who are inves-
4 tigating compliance with this title if the information
5 is relevant to the investigation; or

6 (5) to the extent that such disclosure is made
7 in connection with the employee's compliance with
8 the certification provisions of section 103 of the
9 Family and Medical Leave Act of 1993 (29 U.S.C.
10 2613) or such requirements under State family and
11 medical leave laws.

12 **SEC. 207. REMEDIES AND ENFORCEMENT.**

13 (a) EMPLOYEES COVERED BY TITLE VII OF THE
14 CIVIL RIGHTS ACT OF 1964.—

15 (1) IN GENERAL.—The powers, remedies, and
16 procedures provided in sections 705, 706, 707, 709,
17 710, and 711 of the Civil Rights Act of 1964 (42
18 U.S.C. 2000e–4 et seq.) to the Commission, the At-
19 torney General, or any person, alleging a violation of
20 title VII of that Act (42 U.S.C. 2000e et seq.) shall
21 be the powers, remedies, and procedures this title
22 provides to the Commission, the Attorney General,
23 or any person, respectively, alleging an unlawful em-
24 ployment practice in violation of this title against an

1 employee described in section 201(2)(A)(i), except as
2 provided in paragraphs (2) and (3).

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

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

19 (b) EMPLOYEES COVERED BY GOVERNMENT EM-
20 PLOYEE RIGHTS ACT OF 1991.—

21 (1) IN GENERAL.—The powers, remedies, and
22 procedures provided in sections 302 and 304 of the
23 Government Employee Rights Act of 1991 (42
24 U.S.C. 2000e–16b, 2000e–16c) to the Commission,
25 or any person, alleging a violation of section

1 302(a)(1) of that Act (42 U.S.C. 2000e–16b(a)(1))
2 shall be the powers, remedies, and procedures this
3 title provides to the Commission, or any person, re-
4 spectively, alleging an unlawful employment practice
5 in violation of this title against an employee de-
6 scribed in section 201(2)(A)(ii), except as provided
7 in paragraphs (2) and (3).

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

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

23 (c) EMPLOYEES COVERED BY CONGRESSIONAL AC-
24 COUNTABILITY ACT OF 1995.—

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

13 (2) COSTS AND FEES.—The powers, remedies,
14 and procedures provided in subsections (b) and (c)
15 of section 722 of the Revised Statutes (42 U.S.C.
16 1988), shall be powers, remedies, and procedures
17 this title provides to that Board, or any person, al-
18 leging such a practice.

19 (3) DAMAGES.—The powers, remedies, and pro-
20 cedures provided in section 1977A of the Revised
21 Statutes (42 U.S.C. 1981a), including the limita-
22 tions contained in subsection (b)(3) of such section
23 1977A, shall be powers, remedies, and procedures
24 this title provides to that Board, or any person, al-
25 leging such a practice (not an employment practice

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

3 (4) OTHER APPLICABLE PROVISIONS.—With re-
4 spect to a claim alleging a practice described in
5 paragraph (1), title III of the Congressional Ac-
6 countability Act of 1995 (2 U.S.C. 1381 et seq.)
7 shall apply in the same manner as such title applies
8 with respect to a claim alleging a violation of section
9 201(a)(1) of such Act (2 U.S.C. 1311(a)(1)).

10 (d) EMPLOYEES COVERED BY CHAPTER 5 OF TITLE
11 3, UNITED STATES CODE.—

12 (1) IN GENERAL.—The powers, remedies, and
13 procedures provided in chapter 5 of title 3, United
14 States Code, to the President, the Commission, the
15 Merit Systems Protection Board, or any person, al-
16 leging a violation of section 411(a)(1) of that title,
17 shall be the powers, remedies, and procedures this
18 title provides to the President, the Commission, such
19 Board, or any person, respectively, alleging an un-
20 lawful employment practice in violation of this title
21 against an employee described in section
22 201(2)(A)(iv), except as provided in paragraphs (2)
23 and (3).

24 (2) COSTS AND FEES.—The powers, remedies,
25 and procedures provided in subsections (b) and (c)

1 of section 722 of the Revised Statutes (42 U.S.C.
2 1988), shall be powers, remedies, and procedures
3 this title provides to the President, the Commission,
4 such Board, or any person, alleging such a practice.

5 (3) DAMAGES.—The powers, remedies, and pro-
6 cedures provided in section 1977A of the Revised
7 Statutes (42 U.S.C. 1981a), including the limita-
8 tions contained in subsection (b)(3) of such section
9 1977A, shall be powers, remedies, and procedures
10 this title provides to the President, the Commission,
11 such Board, or any person, alleging such a practice
12 (not an employment practice specifically excluded
13 from coverage under section 1977A(a)(1) of the Re-
14 vised Statutes).

15 (e) EMPLOYEES COVERED BY SECTION 717 OF THE
16 CIVIL RIGHTS ACT OF 1964.—

17 (1) IN GENERAL.—The powers, remedies, and
18 procedures provided in section 717 of the Civil
19 Rights Act of 1964 (42 U.S.C. 2000e–16) to the
20 Commission, the Attorney General, the Librarian of
21 Congress, or any person, alleging a violation of that
22 section shall be the powers, remedies, and proce-
23 dures this title provides to the Commission, the At-
24 torney General, the Librarian of Congress, or any
25 person, respectively, alleging an unlawful employ-

1 ment practice in violation of this title against an em-
2 ployee or applicant described in section
3 201(2)(A)(v), except as provided in paragraphs (2)
4 and (3).

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

12 (3) DAMAGES.—The powers, remedies, and pro-
13 cedures provided in section 1977A of the Revised
14 Statutes (42 U.S.C. 1981a), including the limita-
15 tions contained in subsection (b)(3) of such section
16 1977A, shall be powers, remedies, and procedures
17 this title provides to the Commission, the Attorney
18 General, the Librarian of Congress, or any person,
19 alleging such a practice (not an employment practice
20 specifically excluded from coverage under section
21 1977A(a)(1) of the Revised Statutes).

22 (f) DEFINITION.—In this section, the term “Commis-
23 sion” means the Equal Employment Opportunity Commis-
24 sion.

1 **SEC. 208. DISPARATE IMPACT.**

2 (a) GENERAL RULE.—Notwithstanding any other
3 provision of this Act, “disparate impact”, as that term is
4 used in section 703(k) of the Civil Rights Act of 1964
5 (42 U.S.C. 2000e–d(k)), on the basis of genetic informa-
6 tion does not establish a cause of action under this Act.

7 (b) COMMISSION.—On the date that is 6 years after
8 the date of enactment of this Act, there shall be estab-
9 lished a commission, to be known as the Genetic Non-
10 discrimination Study Commission (referred to in this sec-
11 tion as the “Commission”) to review the developing
12 science of genetics and to make recommendations to Con-
13 gress regarding whether to provide a disparate impact
14 cause of action under this Act.

15 (c) MEMBERSHIP.—

16 (1) IN GENERAL.—The Commission shall be
17 composed of 8 members, of which—

18 (A) 1 member shall be appointed by the
19 Majority Leader of the Senate;

20 (B) 1 member shall be appointed by the
21 Minority Leader of the Senate;

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

25 (D) 1 member shall be appointed by the
26 ranking minority member of the Committee on

1 Health, Education, Labor, and Pensions of the
2 Senate;

3 (E) 1 member shall be appointed by the
4 Speaker of the House of Representatives;

5 (F) 1 member shall be appointed by the
6 Minority Leader of the House of Representa-
7 tives;

8 (G) 1 member shall be appointed by the
9 Chairman of the Committee on Education and
10 the Workforce of the House of Representatives;
11 and

12 (H) 1 member shall be appointed by the
13 ranking minority member of the Committee on
14 Education and the Workforce of the House of
15 Representatives.

16 (2) COMPENSATION AND EXPENSES.—The
17 members of the Commission shall not receive com-
18 pensation for the performance of services for the
19 Commission, but shall be allowed travel expenses, in-
20 cluding per diem in lieu of subsistence, at rates au-
21 thorized for employees of agencies under subchapter
22 I of chapter 57 of title 5, United States Code, while
23 away from their homes or regular places of business
24 in the performance of services for the Commission.

25 (d) ADMINISTRATIVE PROVISIONS.—

1 (1) LOCATION.—The Commission shall be lo-
2 cated in a facility maintained by the Equal Employ-
3 ment Opportunity Commission.

4 (2) DETAIL OF GOVERNMENT EMPLOYEES.—
5 Any Federal Government employee may be detailed
6 to the Commission without reimbursement, and such
7 detail shall be without interruption or loss of civil
8 service status or privilege.

9 (3) INFORMATION FROM FEDERAL AGENCIES.—
10 The Commission may secure directly from any Fed-
11 eral department or agency such information as the
12 Commission considers necessary to carry out the
13 provisions of this section. Upon request of the Com-
14 mission, the head of such department or agency
15 shall furnish such information to the Commission.

16 (4) HEARINGS.—The Commission may hold
17 such hearings, sit and act at such times and places,
18 take such testimony, and receive such evidence as
19 the Commission considers advisable to carry out the
20 objectives of this section, except that, to the extent
21 possible, the Commission shall use existing data and
22 research.

23 (5) POSTAL SERVICES.—The Commission may
24 use the United States mails in the same manner and

1 under the same conditions as other departments and
2 agencies of the Federal Government.

3 (e) REPORT.—Not later than 1 year after all of the
4 members are appointed to the Commission under sub-
5 section (c)(1), the Commission shall submit to Congress
6 a report that summarizes the findings of the Commission
7 and makes such recommendations for legislation as are
8 consistent with this Act.

9 (f) AUTHORIZATION OF APPROPRIATIONS.—There
10 are authorized to be appropriated to the Equal Employ-
11 ment Opportunity Commission such sums as may be nec-
12 essary to carry out this section.

13 **SEC. 209. CONSTRUCTION.**

14 Nothing in this title shall be construed to—

15 (1) limit the rights or protections of an indi-
16 vidual under the Americans with Disabilities Act of
17 1990 (42 U.S.C. 12101 et seq.), including coverage
18 afforded to individuals under section 102 of such
19 Act (42 U.S.C. 12112), or under the Rehabilitation
20 Act of 1973 (29 U.S.C. 701 et seq.);

21 (2)(A) limit the rights or protections of an indi-
22 vidual to bring an action under this title against an
23 employer, employment agency, labor organization, or
24 joint labor-management committee for a violation of
25 this title; or

1 (B) establish a violation under this title for an
2 employer, employment agency, labor organization, or
3 joint labor-management committee of a provision of
4 the amendments made by title I;

5 (3) limit the rights or protections of an indi-
6 vidual under any other Federal or State statute that
7 provides equal or greater protection to an individual
8 than the rights or protections provided for under
9 this title;

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

12 (5) limit or expand the protections, rights, or
13 obligations of employees or employers under applica-
14 ble workers' compensation laws;

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

21 (7) limit the statutory or regulatory authority
22 of the Occupational Safety and Health Administra-
23 tion or the Mine Safety and Health Administration
24 to promulgate or enforce workplace safety and
25 health laws and regulations.

1 **SEC. 210. MEDICAL INFORMATION THAT IS NOT GENETIC**
2 **INFORMATION.**

3 An employer, employment agency, labor organization,
4 or joint labor-management committee shall not be consid-
5 ered to be in violation of this title based on the use, acqui-
6 sition, or disclosure of medical information that is not ge-
7 netic information about a manifested disease, disorder, or
8 pathological condition of an employee or member, includ-
9 ing a manifested disease, disorder, or pathological condi-
10 tion that has or may have a genetic basis.

11 **SEC. 211. REGULATIONS.**

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

15 **SEC. 212. AUTHORIZATION OF APPROPRIATIONS.**

16 There are authorized to be appropriated such sums
17 as may be necessary to carry out this title (except for sec-
18 tion 208).

19 **SEC. 213. EFFECTIVE DATE.**

20 This title takes effect on the date that is 18 months
21 after the date of enactment of this Act.

22 **TITLE III—MISCELLANEOUS**
23 **PROVISION**

24 **SEC. 301. SEVERABILITY.**

25 If any provision of this Act, an amendment made by
26 this Act, or the application of such provision or amend-

1 ment to any person or circumstance is held to be unconsti-
2 tutional, the remainder of this Act, the amendments made
3 by this Act, and the application of such provisions to any
4 person or circumstance shall not be affected thereby.

Passed the Senate October 14, 2003.

Attest:

Secretary.

108TH CONGRESS
1ST SESSION

S. 1053

AN ACT

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