

110TH CONGRESS  
1ST SESSION

# H. R. 493

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

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## IN THE HOUSE OF REPRESENTATIVES

JANUARY 16, 2007

Ms. SLAUGHTER (for herself, Mrs. BIGGERT, Ms. ESHOO, Mr. WALDEN of Oregon, Mr. GEORGE MILLER of California, Mr. DINGELL, Mr. RANGEL, Mr. ACKERMAN, Mr. ALEXANDER, Mr. ALLEN, Mr. BACHUS, Mr. BAKER, Ms. BALDWIN, Mr. BARTLETT of Maryland, Mr. BILIRAKIS, Mrs. BLACKBURN, Mr. BLUMENAUER, Mrs. BONO, Mr. BOUSTANY, Mr. BROWN of South Carolina, Ms. GINNY BROWN-WAITE of Florida, Mr. BURTON of Indiana, Mr. CALVERT, Mrs. CAPITO, Mrs. CAPPS, Mr. CAPUANO, Mr. CASTLE, Mr. CHABOT, Mr. CHANDLER, Mr. COLE of Oklahoma, Mr. CONAWAY, Mr. CONYERS, Mrs. DAVIS of California, Mr. TOM DAVIS of Virginia, Mr. DAVIS of Kentucky, Ms. DEGETTE, Mr. DICKS, Mr. DOGGETT, Mrs. DRAKE, Mr. DUNCAN, Mr. EHLERS, Mr. EMANUEL, Mrs. EMERSON, Mr. ENGEL, Mr. ENGLISH of Pennsylvania, Mr. FARR, Mr. FERGUSON, Mr. FRELINGHUYSEN, Mr. GALLEGLY, Mr. GERLACH, Mr. GILCHREST, Mr. GILLMOR, Mr. GOHMERT, Ms. GRANGER, Mr. GENE GREEN of Texas, Mr. GRIJALVA, Mr. HALL of Texas, Mr. HASTINGS of Washington, Mr. HERGER, Ms. HERSETH, Mr. HINOJOSA, Ms. HIRONO, Mr. HOBSON, Mr. HOEKSTRA, Ms. HOOLEY, Mr. HUNTER, Mr. ISRAEL, Mr. JOHNSON of Illinois, Mr. JONES of North Carolina, Mr. KANJORSKI, Mr. KENNEDY, Mr. KILDEE, Mr. KING of New York, Mr. KIRK, Mr. KUCINICH, Mr. KUHL of New York, Mr. LAHOOD, Mr. LATHAM, Mr. LEWIS of Kentucky, Mr. LIPINSKI, Mr. LOBIONDO, Ms. ZOE LOFGREN of California, Mr. LUCAS, Mrs. MALONEY of New York, Mr. MANZULLO, Mr. MARCHANT, Mr. MCCAUL of Texas, Ms. MCCOLLUM of Minnesota, Mr. MCCOTTER, Mr. MCHUGH, Mr. McNULTY, Mr. MICA, Mr. MORAN of Virginia, Mrs. MYRICK, Mr. NEUGEBAUER, Mr. NORWOOD, Mr. OLVER, Mr. PEARCE, Mr. PITTS, Mr. PLATTS, Mr. PORTER, Mr. PRICE of North Carolina, Ms. PRYCE of Ohio, Mr. PUTNAM, Mr. RAMSTAD, Mr. REGULA, Mr. REICHERT, Mr. REYNOLDS, Mr. ROSKAM, Ms. ROS-LEHTINEN, Mr. RYAN of Wisconsin, Mr. SAXTON, Ms. SCHAKOWSKY, Mr. SCHIFF, Mr. SESSIONS, Mr. SHAYS, Mr. SIMPSON, Ms. SOLIS, Mr. SOUDER, Mr. STARK, Mr. THOMPSON of California, Mr. TIBERI, Mr. TIERNEY, Mr. UDALL of New Mexico, Mr. UPTON, Mr. VAN HOLLEN, Mr. WALSH of New York, Mr. WAMP, Ms. WATSON, Mr. WAX-

MAN, Mr. WELLER of Illinois, Mr. WEXLER, Mr. WHITFIELD, Mr. WICKER, Mr. WILSON of South Carolina, Mr. WOLF, Ms. WOOLSEY, Mr. YARMUTH, Mr. YOUNG of Florida, Mr. CROWLEY, Mr. HOLT, Mr. JINDAL, Mr. LATOURETTE, and Mr. TANCREDO) introduced the following bill; which was referred to the Committee on Education and Labor, and in addition to the Committees on Energy and Commerce and Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

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## A BILL

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

1       *Be it enacted by the Senate and House of Representa-*  
 2       *tives of the United States of America in Congress assembled,*

3       **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

4       (a) SHORT TITLE.—This Act may be cited as the  
 5       “Genetic Information Nondiscrimination Act of 2007”.

6       (b) TABLE OF CONTENTS.—The table of contents of  
 7       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 title XVIII of the Social Security Act relating to medigap.

Sec. 104. Privacy and confidentiality.

Sec. 105. Assuring coordination.

Sec. 106. 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.

### 1 **SEC. 2. FINDINGS.**

2 Congress makes the following findings:

3 (1) Deciphering the sequence of the human ge-  
4 nome and other advances in genetics open major  
5 new opportunities for medical progress. New knowl-  
6 edge about the genetic basis of illness will allow for  
7 earlier detection of illnesses, often before symptoms  
8 have begun. Genetic testing can allow individuals to  
9 take steps to reduce the likelihood that they will con-  
10 tract a particular disorder. New knowledge about ge-  
11 netics may allow for the development of better thera-  
12 pies that are more effective against disease or have  
13 fewer side effects than current treatments. These  
14 advances give rise to the potential misuse of genetic  
15 information to discriminate in health insurance and  
16 employment.

17 (2) The early science of genetics became the  
18 basis of State laws that provided for the sterilization  
19 of persons having presumed genetic “defects” such

1 as mental retardation, mental disease, epilepsy,  
2 blindness, and hearing loss, among other conditions.  
3 The first sterilization law was enacted in the State  
4 of Indiana in 1907. By 1981, a majority of States  
5 adopted sterilization laws to “correct” apparent ge-  
6 netic traits or tendencies. Many of these State laws  
7 have since been repealed, and many have been modi-  
8 fied to include essential constitutional requirements  
9 of due process and equal protection. However, the  
10 current explosion in the science of genetics, and the  
11 history of sterilization laws by the States based on  
12 early genetic science, compels Congressional action  
13 in this area.

14 (3) Although genes are facially neutral markers,  
15 many genetic conditions and disorders are associated  
16 with particular racial and ethnic groups and gender.  
17 Because some genetic traits are most prevalent in  
18 particular groups, members of a particular group  
19 may be stigmatized or discriminated against as a re-  
20 sult of that genetic information. This form of dis-  
21 crimination was evident in the 1970s, which saw the  
22 advent of programs to screen and identify carriers of  
23 sickle cell anemia, a disease which afflicts African-  
24 Americans. Once again, State legislatures began to  
25 enact discriminatory laws in the area, and in the

1 early 1970s began mandating genetic screening of  
2 all African Americans for sickle cell anemia, leading  
3 to discrimination and unnecessary fear. To alleviate  
4 some of this stigma, Congress in 1972 passed the  
5 National Sickle Cell Anemia Control Act, which  
6 withholds Federal funding from States unless sickle  
7 cell testing is voluntary.

8 (4) Congress has been informed of examples of  
9 genetic discrimination in the workplace. These in-  
10 clude the use of pre-employment genetic screening at  
11 Lawrence Berkeley Laboratory, which led to a court  
12 decision in favor of the employees in that case *Nor-*  
13 *man-Bloodsaw v. Lawrence Berkeley Laboratory*  
14 (135 F.3d 1260, 1269 (9th Cir. 1998)). Congress  
15 clearly has a compelling public interest in relieving  
16 the fear of discrimination and in prohibiting its ac-  
17 tual practice in employment and health insurance.

18 (5) Federal law addressing genetic discrimina-  
19 tion in health insurance and employment is incom-  
20 plete in both the scope and depth of its protections.  
21 Moreover, while many States have enacted some type  
22 of genetic non-discrimination law, these laws vary  
23 widely with respect to their approach, application,  
24 and level of protection. Congress has collected sub-  
25 stantial evidence that the American public and the

1 medical community find the existing patchwork of  
2 State and Federal laws to be confusing and inad-  
3 equate to protect them from discrimination. There-  
4 fore Federal legislation establishing a national and  
5 uniform basic standard is necessary to fully protect  
6 the public from discrimination and allay their con-  
7 cerns about the potential for discrimination, thereby  
8 allowing individuals to take advantage of genetic  
9 testing, technologies, research, and new therapies.

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

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

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

18 (1) NO ENROLLMENT RESTRICTION FOR GE-  
19 NETIC SERVICES.—Section 702(a)(1)(F) of the Em-  
20 ployee Retirement Income Security Act of 1974 (29  
21 U.S.C. 1182(a)(1)(F)) is amended by inserting be-  
22 fore the period the following: “(including informa-  
23 tion about a request for or receipt of genetic services  
24 by an individual or family member of such indi-  
25 vidual)”.

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

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

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

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

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

24                   “(c) GENETIC TESTING.—

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

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

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

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

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



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

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

9       “(n) ENFORCEMENT OF GENETIC NONDISCRIMINA-  
10 TION REQUIREMENTS.—

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

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

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

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

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

18           “(B) ADMINISTRATIVE PENALTY.—

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

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

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

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

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

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

15 “(3) SECRETARIAL ENFORCEMENT AUTHOR-  
16 ITY.—

17 “(A) GENERAL RULE.—The Secretary has  
18 the authority to impose a penalty on any failure  
19 of a group health plan to meet the requirements  
20 of subsection (a)(1)(F), (b)(3), or (c) of section  
21 702.

22 “(B) AMOUNT.—

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

1 compliance period with respect to each in-  
2 dividual to whom such failure relates.

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

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

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

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

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

17 “(I) which are not corrected be-  
18 fore the date on which the plan re-  
19 ceives a notice from the Secretary of  
20 such violation; and

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

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

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

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

11 “(D) LIMITATIONS.—

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

22 “(ii) PENALTY NOT TO APPLY TO  
23 FAILURES CORRECTED WITHIN CERTAIN  
24 PERIODS.—No penalty shall be imposed by  
25 subparagraph (A) on any failure if—

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

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

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

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

22           “(II) \$500,000.

23           “(E) WAIVER BY SECRETARY.—In the case  
24           of a failure which is due to reasonable cause  
25           and not to willful neglect, the Secretary may

1 waive part or all of the penalty imposed by sub-  
2 paragraph (A) to the extent that the payment  
3 of such penalty would be excessive relative to  
4 the failure involved.”.

5 (d) DEFINITIONS.—Section 733(d) of the Employee  
6 Retirement Income Security Act of 1974 (29 U.S.C.  
7 1191b(d)) is amended by adding at the end the following:

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

10 “(A) the spouse of the individual;

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

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

17 “(6) GENETIC INFORMATION.—

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

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

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

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

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

7                   “(7) GENETIC TEST.—

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

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

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

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



1           “(8) GENETIC SERVICES.—The term ‘genetic  
2 services’ means—

3                   “(A) a genetic test;

4                   “(B) genetic counseling (such as obtaining,  
5 interpreting, or assessing genetic information);

6           or

7                   “(C) genetic education.”.

8           (e) REGULATIONS AND EFFECTIVE DATE.—

9                   (1) REGULATIONS.—Not later than 1 year after  
10 the date of enactment of this title, the Secretary of  
11 Labor shall issue final regulations in an accessible  
12 format to carry out the amendments made by this  
13 section.

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

19 **SEC. 102. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**  
20 **ACT.**

21           (a) AMENDMENTS RELATING TO THE GROUP MAR-  
22 KET.—

23                   (1) PROHIBITION OF HEALTH DISCRIMINATION  
24 ON THE BASIS OF GENETIC INFORMATION OR GE-  
25 NETIC SERVICES.—

1 (A) NO ENROLLMENT RESTRICTION FOR  
2 GENETIC SERVICES.—Section 2702(a)(1)(F) of  
3 the Public Health Service Act (42 U.S.C.  
4 300gg–1(a)(1)(F)) is amended by inserting be-  
5 fore the period the following: “(including infor-  
6 mation about a request for or receipt of genetic  
7 services by an individual or family member of  
8 such individual)”.

9 (B) NO DISCRIMINATION IN GROUP PRE-  
10 MIUMS BASED ON GENETIC INFORMATION.—  
11 Section 2702(b) of the Public Health Service  
12 Act (42 U.S.C. 300gg–1(b)) is amended—

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

16 (ii) by adding at the end the fol-  
17 lowing:

18 “(3) NO DISCRIMINATION IN GROUP PREMIUMS  
19 BASED ON GENETIC INFORMATION.—For purposes  
20 of this section, a group health plan, or a health in-  
21 surance issuer offering group health insurance cov-  
22 erage in connection with a group health plan, shall  
23 not adjust premium or contribution amounts for a  
24 group on the basis of genetic information concerning  
25 an individual in the group or a family member of the

1 individual (including information about a request for  
2 or receipt of genetic services by an individual or  
3 family member of such individual).”.

4 (2) LIMITATIONS ON GENETIC TESTING.—Sec-  
5 tion 2702 of the Public Health Service Act (42  
6 U.S.C. 300gg–1) is amended by adding at the end  
7 the following:

8 “(c) GENETIC TESTING.—

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

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

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

22 “(B) limit the authority of a health care  
23 professional who is employed by or affiliated  
24 with a group health plan or a health insurance  
25 issuer and who is providing health care services

1 to an individual as part of a bona fide wellness  
2 program to notify such individual of the avail-  
3 ability of a genetic test or to provide informa-  
4 tion to such individual regarding such genetic  
5 test; or

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

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

13 (3) REMEDIES AND ENFORCEMENT.—Section  
14 2722(b) of the Public Health Service Act (42 U.S.C.  
15 300gg–22(b)) is amended by adding at the end the  
16 following:

17 “(3) ENFORCEMENT AUTHORITY RELATING TO  
18 GENETIC DISCRIMINATION.—

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

1 the requirements of subsection (a)(1)(F),  
2 (b)(3), or (c) of section 2702.

3 “(B) AMOUNT.—

4 “(i) IN GENERAL.—The amount of  
5 the penalty imposed under this paragraph  
6 shall be \$100 for each day in the non-  
7 compliance period with respect to each in-  
8 dividual to whom such failure relates.

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

13 “(I) beginning on the date such  
14 failure first occurs; and

15 “(II) ending on the date such  
16 failure is corrected.

17 “(C) MINIMUM PENALTIES WHERE FAIL-  
18 URE DISCOVERED.—Notwithstanding clauses (i)  
19 and (ii) of subparagraph (D):

20 “(i) IN GENERAL.—In the case of 1 or  
21 more failures with respect to an indi-  
22 vidual—

23 “(I) which are not corrected be-  
24 fore the date on which the plan re-

1 ceives a notice from the Secretary of  
2 such violation; and

3 “(II) which occurred or continued  
4 during the period involved;

5 the amount of penalty imposed by subpara-  
6 graph (A) by reason of such failures with  
7 respect to such individual shall not be less  
8 than \$2,500.

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

17 “(D) LIMITATIONS.—

18 “(i) PENALTY NOT TO APPLY WHERE  
19 FAILURE NOT DISCOVERED EXERCISING  
20 REASONABLE DILIGENCE.—No penalty  
21 shall be imposed by subparagraph (A) on  
22 any failure during any period for which it  
23 is established to the satisfaction of the  
24 Secretary that the person otherwise liable  
25 for such penalty did not know, and exer-

1 cising reasonable diligence would not have  
2 known, that such failure existed.

3 “(ii) PENALTY NOT TO APPLY TO  
4 FAILURES CORRECTED WITHIN CERTAIN  
5 PERIODS.—No penalty shall be imposed by  
6 subparagraph (A) on any failure if—

7 “(I) such failure was due to rea-  
8 sonable cause and not to willful ne-  
9 glect; and

10 “(II) such failure is corrected  
11 during the 30-day period beginning on  
12 the first date the person otherwise lia-  
13 ble for such penalty knew, or exer-  
14 cising reasonable diligence would have  
15 known, that such failure existed.

16 “(iii) OVERALL LIMITATION FOR UN-  
17 INTENTIONAL FAILURES.—In the case of  
18 failures which are due to reasonable cause  
19 and not to willful neglect, the penalty im-  
20 posed by subparagraph (A) for failures  
21 shall not exceed the amount equal to the  
22 lesser of—

23 “(I) 10 percent of the aggregate  
24 amount paid or incurred by the em-  
25 ployer (or predecessor employer) dur-

1                   ing the preceding taxable year for  
2                   group health plans; or

3                   “(II) \$500,000.

4                   “(E) WAIVER BY SECRETARY.—In the case  
5                   of a failure which is due to reasonable cause  
6                   and not to willful neglect, the Secretary may  
7                   waive part or all of the penalty imposed by sub-  
8                   paragraph (A) to the extent that the payment  
9                   of such penalty would be excessive relative to  
10                  the failure involved.”

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

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

16                         “(A) the spouse of the individual;

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

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

23                  “(16) GENETIC INFORMATION.—



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

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

5                   “(ii) the genetic tests of family mem-  
6 bers of the individual; or

7                   “(iii) the occurrence of a disease or  
8 disorder in family members of the indi-  
9 vidual.

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

13           “(17) GENETIC TEST.—

14                   “(A) IN GENERAL.—The term ‘genetic  
15 test’ means an analysis of human DNA, RNA,  
16 chromosomes, proteins, or metabolites, that de-  
17 tects genotypes, mutations, or chromosomal  
18 changes.

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

21                   “(i) an analysis of proteins or metabo-  
22 lites that does not detect genotypes,  
23 mutations, or chromosomal changes; or

24                   “(ii) an analysis of proteins or me-  
25 tabolites that is directly related to a mani-

1            fested disease, disorder, or pathological  
 2            condition that could reasonably be detected  
 3            by a health care professional with appro-  
 4            priate training and expertise in the field of  
 5            medicine involved.

6            “(18) GENETIC SERVICES.—The term ‘genetic  
 7            services’ means—

8                    “(A) a genetic test;

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

11            or

12                    “(C) genetic education.”.

13            (b) AMENDMENT RELATING TO THE INDIVIDUAL  
 14            MARKET.—

15                    (1) IN GENERAL.—The first subpart 3 of part  
 16            B of title XXVII of the Public Health Service Act  
 17            (42 U.S.C. 300gg–51 et seq.) (relating to other re-  
 18            quirements) is amended—

19                    (A) by redesignating such subpart as sub-  
 20            part 2; and

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

22            **“SEC. 2753. PROHIBITION OF HEALTH DISCRIMINATION ON**  
 23                    **THE BASIS OF GENETIC INFORMATION.**

24                    “(a) PROHIBITION ON GENETIC INFORMATION AS A  
 25            CONDITION OF ELIGIBILITY.—A health insurance issuer

1 offering health insurance coverage in the individual mar-  
2 ket may not establish rules for the eligibility (including  
3 continued eligibility) of any individual to enroll in indi-  
4 vidual health insurance coverage based on genetic infor-  
5 mation (including information about a request for or re-  
6 ceipt of genetic services by an individual or family member  
7 of such individual).

8       “(b) PROHIBITION ON GENETIC INFORMATION IN  
9 SETTING PREMIUM RATES.—A health insurance issuer of-  
10 fering health insurance coverage in the individual market  
11 shall not adjust premium or contribution amounts for an  
12 individual on the basis of genetic information concerning  
13 the individual or a family member of the individual (in-  
14 cluding information about a request for or receipt of ge-  
15 netic services by an individual or family member of such  
16 individual).

17       “(c) GENETIC TESTING.—

18               “(1) LIMITATION ON REQUESTING OR REQUIR-  
19 ING GENETIC TESTING.—A health insurance issuer  
20 offering health insurance coverage in the individual  
21 market shall not request or require an individual or  
22 a family member of such individual to undergo a ge-  
23 netic 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 health insurance issuer and who is pro-  
9 viding health care services to an individual as  
10 part of a bona fide wellness program to notify  
11 such individual of the availability of a genetic  
12 test or to provide information to such individual  
13 regarding 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           (2) REMEDIES AND ENFORCEMENT.—Section  
18 2761(b) of the Public Health Service Act (42 U.S.C.  
19 300gg–61(b)) is amended to read as follows:

20           “(b) SECRETARIAL ENFORCEMENT AUTHORITY.—  
21 The Secretary shall have the same authority in relation  
22 to enforcement of the provisions of this part with respect  
23 to issuers of health insurance coverage in the individual  
24 market in a State as the Secretary has under section  
25 2722(b)(2), and section 2722(b)(3) with respect to viola-

1 tions of genetic nondiscrimination provisions, in relation  
 2 to the enforcement of the provisions of part A with respect  
 3 to issuers of health insurance coverage in the small group  
 4 market in the State.”.

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

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

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

14 “(D) ELECTION NOT APPLICABLE TO RE-  
 15 QUIREMENTS CONCERNING GENETIC INFORMA-  
 16 TION.—The election described in subparagraph  
 17 (A) shall not be available with respect to the  
 18 provisions of subsections (a)(1)(F) and (c) of  
 19 section 2702 and the provisions of section  
 20 2702(b) to the extent that such provisions  
 21 apply to genetic information (or information  
 22 about a request for or the receipt of genetic  
 23 services by an individual or a family member of  
 24 such individual).”.

25 (d) REGULATIONS AND EFFECTIVE DATE.—

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

7           (2) EFFECTIVE DATE.—The amendments made  
8 by this section shall apply—

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

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

19 **SEC. 103. AMENDMENTS TO TITLE XVIII OF THE SOCIAL SE-**  
20 **CURITY ACT RELATING TO MEDIGAP.**

21 (a) NONDISCRIMINATION.—

22           (1) IN GENERAL.—Section 1882(s)(2) of the  
23 Social Security Act (42 U.S.C. 1395ss(s)(2)) is  
24 amended by adding at the end the following:

1           “(E)(i) An issuer of a medicare supple-  
2           mental policy shall not deny or condition the  
3           issuance or effectiveness of the policy, and shall  
4           not discriminate in the pricing of the policy (in-  
5           cluding the adjustment of premium rates) of an  
6           eligible individual on the basis of genetic infor-  
7           mation concerning the individual (or informa-  
8           tion about a request for, or the receipt of, ge-  
9           netic services by such individual or family mem-  
10          ber of such individual).

11           “(ii) For purposes of clause (i), the terms  
12          ‘family member’, ‘genetic services’, and ‘genetic  
13          information’ shall have the meanings given such  
14          terms in subsection (x).”.

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

19          (b) LIMITATIONS ON GENETIC TESTING.—

20           (1) IN GENERAL.—Section 1882 of the Social  
21          Security Act (42 U.S.C. 1395ss) is amended by add-  
22          ing at the end the following:

23          “(x) LIMITATIONS ON GENETIC TESTING.—

24           “(1) GENETIC TESTING.—

1           “(A) LIMITATION ON REQUESTING OR RE-  
2           QUIRING GENETIC TESTING.—An issuer of a  
3           medicare supplemental policy shall not request  
4           or require an individual or a family member of  
5           such individual to undergo a genetic test.

6           “(B) RULE OF CONSTRUCTION.—Nothing  
7           in this title shall be construed to—

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

14                  “(ii) limit the authority of a health  
15                  care professional who is employed by or af-  
16                  filiated with an issuer of a medicare sup-  
17                  plemental policy and who is providing  
18                  health care services to an individual as  
19                  part of a bona fide wellness program to no-  
20                  tify such individual of the availability of a  
21                  genetic test or to provide information to  
22                  such individual regarding such genetic test;  
23                  or



1           “(iii) authorize or permit a health  
2           care professional to require that an indi-  
3           vidual undergo a genetic test.

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

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

7                   “(i) the spouse of the individual;

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

11                   “(iii) any other individuals related by  
12          blood to the individual or to the spouse or  
13          child described in clause (i) or (ii).

14          “(B) GENETIC INFORMATION.—

15                   “(i) IN GENERAL.—Except as pro-  
16          vided in clause (ii), the term ‘genetic infor-  
17          mation’ means information about—

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

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

21                           “(III) the occurrence of a disease  
22          or disorder in family members of the  
23          individual.

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

4                   “(C) GENETIC TEST.—

5                   “(i) IN GENERAL.—The term ‘genetic  
6 test’ means an analysis of human DNA,  
7 RNA, chromosomes, proteins, or metabo-  
8 lites, that detects genotypes, mutations, or  
9 chromosomal changes.

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

12                   “(I) an analysis of proteins or  
13 metabolites that does not detect  
14 genotypes, mutations, or chromosomal  
15 changes; or

16                   “(II) an analysis of proteins or  
17 metabolites that is directly related to  
18 a manifested disease, disorder, or  
19 pathological condition that could rea-  
20 sonably be detected by a health care  
21 professional with appropriate training  
22 and expertise in the field of medicine  
23 involved.

24                   “(D) GENETIC SERVICES.—The term ‘ge-  
25 netic services’ means—

1 “(i) a genetic test;

2 “(ii) genetic counseling (such as ob-  
3 taining, interpreting, or assessing genetic  
4 information); or

5 “(iii) genetic education.

6 “(E) ISSUER OF A MEDICARE SUPPLE-  
7 MENTAL POLICY.—The term ‘issuer of a medi-  
8 care supplemental policy’ includes a third-party  
9 administrator or other person acting for or on  
10 behalf of such issuer.”.

11 (2) CONFORMING AMENDMENT.—Section  
12 1882(o) of the Social Security Act (42 U.S.C.  
13 1395ss(o)) is amended by adding at the end the fol-  
14 lowing:

15 “(4) The issuer of the medicare supplemental  
16 policy complies with subsection (s)(2)(E) and sub-  
17 section (x).”.

18 (3) EFFECTIVE DATE.—The amendments made  
19 by this subsection shall apply with respect to an  
20 issuer of a medicare supplemental policy for policy  
21 years beginning on or after the date that is 18  
22 months after the date of enactment of this Act.

23 (c) TRANSITION PROVISIONS.—

24 (1) IN GENERAL.—If the Secretary of Health  
25 and Human Services identifies a State as requiring

1 a change to its statutes or regulations to conform its  
2 regulatory program to the changes made by this sec-  
3 tion, the State regulatory program shall not be con-  
4 sidered to be out of compliance with the require-  
5 ments of section 1882 of the Social Security Act due  
6 solely to failure to make such change until the date  
7 specified in paragraph (4).

8 (2) NAIC STANDARDS.—If, not later than June  
9 30, 2008, the National Association of Insurance  
10 Commissioners (in this subsection referred to as the  
11 “NAIC”) modifies its NAIC Model Regulation relat-  
12 ing to section 1882 of the Social Security Act (re-  
13 ferred to in such section as the 1991 NAIC Model  
14 Regulation, as subsequently modified) to conform to  
15 the amendments made by this section, such revised  
16 regulation incorporating the modifications shall be  
17 considered to be the applicable NAIC model regula-  
18 tion (including the revised NAIC model regulation  
19 and the 1991 NAIC Model Regulation) for the pur-  
20 poses of such section.

21 (3) SECRETARY STANDARDS.—If the NAIC  
22 does not make the modifications described in para-  
23 graph (2) within the period specified in such para-  
24 graph, the Secretary of Health and Human Services  
25 shall, not later than October 1, 2008, make the

1 modifications described in such paragraph and such  
2 revised regulation incorporating the modifications  
3 shall be considered to be the appropriate regulation  
4 for the purposes of such section.

5 (4) DATE SPECIFIED.—

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

9 (i) the date the State changes its stat-  
10 utes or regulations to conform its regu-  
11 latory program to the changes made by  
12 this section, or

13 (ii) October 1, 2008.

14 (B) ADDITIONAL LEGISLATIVE ACTION RE-  
15 QUIRED.—In the case of a State which the Sec-  
16 retary identifies as—

17 (i) requiring State legislation (other  
18 than legislation appropriating funds) to  
19 conform its regulatory program to the  
20 changes made in this section, but

21 (ii) having a legislature which is not  
22 scheduled to meet in 2008 in a legislative  
23 session in which such legislation may be  
24 considered, the date specified in this para-  
25 graph is the first day of the first calendar

1 quarter beginning after the close of the  
2 first legislative session of the State legisla-  
3 ture that begins on or after July 1, 2008.  
4 For purposes of the previous sentence, in  
5 the case of a State that has a 2-year legis-  
6 lative session, each year of such session  
7 shall be deemed to be a separate regular  
8 session of the State legislature.

9 **SEC. 104. PRIVACY AND CONFIDENTIALITY.**

10 (a) **APPLICABILITY.**—Except as provided in sub-  
11 section (d), the provisions of this section shall apply to  
12 group health plans, health insurance issuers (including  
13 issuers in connection with group health plans or individual  
14 health coverage), and issuers of medicare supplemental  
15 policies, without regard to—

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

18 (2) section 2721(a) of the Public Health Serv-  
19 ice Act (42 U.S.C. 300gg-21(a)); and

20 (3) section 9831(a)(2) of the Internal Revenue  
21 Code of 1986.

22 (b) **COMPLIANCE WITH CERTAIN CONFIDENTIALITY**  
23 **STANDARDS WITH RESPECT TO GENETIC INFORMA-**  
24 **TION.**—

1           (1) IN GENERAL.—The regulations promulgated  
2           by the Secretary of Health and Human Services  
3           under part C of title XI of the Social Security Act  
4           (42 U.S.C. 1320d et seq.) and section 264 of the  
5           Health Insurance Portability and Accountability Act  
6           of 1996 (42 U.S.C. 1320d–2 note) shall apply to the  
7           use or disclosure of genetic information.

8           (2) PROHIBITION ON UNDERWRITING AND PRE-  
9           MIUM RATING.—Notwithstanding paragraph (1), a  
10          group health plan, a health insurance issuer, or  
11          issuer of a medicare supplemental policy shall not  
12          use or disclose genetic information (including infor-  
13          mation about a request for or a receipt of genetic  
14          services by an individual or family member of such  
15          individual) for purposes of underwriting, determina-  
16          tions of eligibility to enroll, premium rating, or the  
17          creation, renewal or replacement of a plan, contract  
18          or coverage for health insurance or health benefits.

19          (c) PROHIBITION ON COLLECTION OF GENETIC IN-  
20          FORMATION.—

21                 (1) IN GENERAL.—A group health plan, health  
22                 insurance issuer, or issuer of a medicare supple-  
23                 mental policy shall not request, require, or purchase  
24                 genetic information (including information about a  
25                 request for or a receipt of genetic services by an in-

1       dividual or family member of such individual) for  
2       purposes of underwriting, determinations of eligi-  
3       bility to enroll, premium rating, or the creation, re-  
4       newal or replacement of a plan, contract or coverage  
5       for health insurance or health benefits.

6               (2) LIMITATION RELATING TO THE COLLEC-  
7       TION OF GENETIC INFORMATION PRIOR TO ENROLL-  
8       MENT.—A group health plan, health insurance  
9       issuer, or issuer of a medicare supplemental policy  
10      shall not request, require, or purchase genetic infor-  
11      mation (including information about a request for or  
12      a receipt of genetic services by an individual or fam-  
13      ily member of such individual) concerning a partici-  
14      pant, beneficiary, or enrollee prior to the enrollment,  
15      and in connection with such enrollment, of such indi-  
16      vidual under the plan, coverage, or policy.

17              (3) INCIDENTAL COLLECTION.—Where a group  
18      health plan, health insurance issuer, or issuer of a  
19      medicare supplemental policy obtains genetic infor-  
20      mation incidental to the requesting, requiring, or  
21      purchasing of other information concerning a partici-  
22      pant, beneficiary, or enrollee, such request, require-  
23      ment, or purchase shall not be considered a violation  
24      of this subsection if—



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

3 (B) any genetic information (including in-  
4 formation about a request for or receipt of ge-  
5 netic services) requested, required, or purchased  
6 is not used or disclosed in violation of sub-  
7 section (b).

8 (d) APPLICATION OF CONFIDENTIALITY STAND-  
9 ARDS.—The provisions of subsections (b) and (c) shall not  
10 apply—

11 (1) to group health plans, health insurance  
12 issuers, or issuers of medicare supplemental policies  
13 that are not otherwise covered under the regulations  
14 promulgated by the Secretary of Health and Human  
15 Services under part C of title XI of the Social Secu-  
16 rity Act (42 U.S.C. 1320d et seq.) and section 264  
17 of the Health Insurance Portability and Account-  
18 ability Act of 1996 (42 U.S.C. 1320d–2 note); and

19 (2) to genetic information that is not considered  
20 to be individually-identifiable health information  
21 under the regulations promulgated by the Secretary  
22 of Health and Human Services under part C of title  
23 XI of the Social Security Act (42 U.S.C. 1320d et  
24 seq.) and section 264 of the Health Insurance Port-

1 ability and Accountability Act of 1996 (42 U.S.C.  
2 1320d–2 note).

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

11 (f) PREEMPTION.—

12 (1) IN GENERAL.—A provision or requirement  
13 under this section or a regulation promulgated under  
14 this section shall supersede any contrary provision of  
15 State law unless such provision of State law imposes  
16 requirements, standards, or implementation speci-  
17 fications that are more stringent than the require-  
18 ments, standards, or implementation specifications  
19 imposed under this section or such regulations. No  
20 penalty, remedy, or cause of action to enforce such  
21 a State law that is more stringent shall be pre-  
22 empted by this section.

23 (2) RULE OF CONSTRUCTION.—Nothing in  
24 paragraph (1) shall be construed to establish a pen-  
25 alty, remedy, or cause of action under State law if

1 such penalty, remedy, or cause of action is not oth-  
2 erwise available under such State law.

3 (g) COORDINATION WITH PRIVACY REGULATIONS.—

4 The Secretary shall implement and administer this section  
5 in a manner that is consistent with the implementation  
6 and administration by the Secretary of the regulations  
7 promulgated by the Secretary of Health and Human Serv-  
8 ices under part C of title XI of the Social Security Act  
9 (42 U.S.C. 1320d et seq.) and section 264 of the Health  
10 Insurance Portability and Accountability Act of 1996 (42  
11 U.S.C. 1320d–2 note).

12 (h) DEFINITIONS.—In this section:

13 (1) GENETIC INFORMATION; GENETIC SERV-  
14 ICES.—The terms “family member”, “genetic infor-  
15 mation”, “genetic services”, and “genetic test” have  
16 the meanings given such terms in section 2791 of  
17 the Public Health Service Act (42 U.S.C. 300gg–  
18 91), as amended by this Act.

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

24 (3) ISSUER OF A MEDICARE SUPPLEMENTAL  
25 POLICY.—The term “issuer of a medicare supple-

1       mental policy” means an issuer described in section  
2       1882 of the Social Security Act (42 U.S.C. 1395ss).

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

5       **SEC. 105. ASSURING COORDINATION.**

6       (a) IN GENERAL.—Except as provided in subsection  
7 (b), the Secretary of the Treasury, the Secretary of Health  
8 and Human Services, and the Secretary of Labor shall en-  
9 sure, through the execution of an interagency memo-  
10 randum of understanding among such Secretaries, that—

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

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

22       (b) AUTHORITY OF THE SECRETARY.—The Secretary  
23 of Health and Human Services has the sole authority to  
24 promulgate regulations to implement section 104.

1 **SEC. 106. REGULATIONS; EFFECTIVE DATE.**

2 (a) REGULATIONS.—Not later than 1 year after the  
3 date of enactment of this title, the Secretary of Labor,  
4 the Secretary of Health and Human Services, and the Sec-  
5 retary of the Treasury shall issue final regulations in an  
6 accessible format to carry out this title.

7 (b) EFFECTIVE DATE.—Except as provided in sec-  
8 tion 103, the amendments made by this title shall take  
9 effect on the date that is 18 months after the date of en-  
10 actment of this Act.

11 **TITLE II—PROHIBITING EM-**  
12 **PLOYMENT DISCRIMINATION**  
13 **ON THE BASIS OF GENETIC**  
14 **INFORMATION**

15 **SEC. 201. DEFINITIONS.**

16 In this title:

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

21 (2) EMPLOYEE; EMPLOYER; EMPLOYMENT  
22 AGENCY; LABOR ORGANIZATION; MEMBER.—

23 (A) IN GENERAL.—The term “employee”  
24 means—

25 (i) an employee (including an appli-  
26 cant), as defined in section 701(f) of the

1 Civil Rights Act of 1964 (42 U.S.C.  
2 2000e(f));

3 (ii) a State employee (including an ap-  
4 plicant) described in section 304(a) of the  
5 Government Employee Rights Act of 1991  
6 (42 U.S.C. 2000e–16e(a));

7 (iii) a covered employee (including an  
8 applicant), as defined in section 101 of the  
9 Congressional Accountability Act of 1995  
10 (2 U.S.C. 1301);

11 (iv) a covered employee (including an  
12 applicant), as defined in section 411(c) of  
13 title 3, United States Code; or

14 (v) an employee or applicant to which  
15 section 717(a) of the Civil Rights Act of  
16 1964 (42 U.S.C. 2000e–16(a)) applies.

17 (B) EMPLOYER.—The term “employer”  
18 means—

19 (i) an employer (as defined in section  
20 701(b) of the Civil Rights Act of 1964 (42  
21 U.S.C. 2000e(b));

22 (ii) an entity employing a State em-  
23 ployee described in section 304(a) of the  
24 Government Employee Rights Act of 1991;

1 (iii) an employing office, as defined in  
2 section 101 of the Congressional Account-  
3 ability Act of 1995;

4 (iv) an employing office, as defined in  
5 section 411(c) of title 3, United States  
6 Code; or

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

9 (C) EMPLOYMENT AGENCY; LABOR ORGA-  
10 NIZATION.—The terms “employment agency”  
11 and “labor organization” have the meanings  
12 given the terms in section 701 of the Civil  
13 Rights Act of 1964 (42 U.S.C. 2000e).

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

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

19 (A) the spouse of the individual;

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

23 (C) all other individuals related by blood to  
24 the individual or the spouse or child described  
25 in subparagraph (A) or (B).

1 (4) GENETIC INFORMATION.—

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

5 (i) an individual’s genetic tests;

6 (ii) the genetic tests of family mem-  
7 bers of the individual; or

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

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

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

23 (6) GENETIC SERVICES.—The term “genetic  
24 services” means—

25 (A) a genetic test;



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

4 (C) genetic education.

5 (7) GENETIC TEST.—

6 (A) IN GENERAL.—The term “genetic  
7 test” means the analysis of human DNA, RNA,  
8 chromosomes, proteins, or metabolites, that de-  
9 tects genotypes, mutations, or chromosomal  
10 changes.

11 (B) EXCEPTION.—The term “genetic test”  
12 does not mean an analysis of proteins or me-  
13 tabolites that does not detect genotypes,  
14 mutations, or chromosomal changes.

15 **SEC. 202. EMPLOYER PRACTICES.**

16 (a) USE OF GENETIC INFORMATION.—It shall be an  
17 unlawful employment practice for an employer—

18 (1) to fail or refuse to hire or to discharge any  
19 employee, or otherwise to discriminate against any  
20 employee with respect to the compensation, terms,  
21 conditions, or privileges of employment of the em-  
22 ployee, because of genetic information with respect  
23 to the employee (or information about a request for  
24 or the receipt of genetic services by such employee  
25 or family member of such employee); or

1           (2) to limit, segregate, or classify the employees  
2           of the employer in any way that would deprive or  
3           tend to deprive any employee of employment oppor-  
4           tunities or otherwise adversely affect the status of  
5           the employee as an employee, because of genetic in-  
6           formation with respect to the employee (or informa-  
7           tion about a request for or the receipt of genetic  
8           services by such employee or family member of such  
9           employee).

10          (b) ACQUISITION OF GENETIC INFORMATION.—It  
11         shall be an unlawful employment practice for an employer  
12         to request, require, or purchase genetic information with  
13         respect to an employee or a family member of the em-  
14         ployee (or information about a request for the receipt of  
15         genetic services by such employee or a family member of  
16         such employee) except—

17                 (1) where an employer inadvertently requests or  
18                 requires family medical history of the employee or  
19                 family member of the employee;

20                 (2) where—

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

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

1           (C) only the employee (or family member  
2           if the family member is receiving genetic serv-  
3           ices) and the licensed health care professional  
4           or 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 employer except in aggregate terms that do  
14          not disclose the identity of specific employees;

15          (3) where an employer requests or requires  
16          family medical history from the employee to comply  
17          with the certification provisions of section 103 of the  
18          Family and Medical Leave Act of 1993 (29 U.S.C.  
19          2613) or such requirements under State family and  
20          medical leave laws;

21          (4) where an employer purchases documents  
22          that are commercially and publicly available (includ-  
23          ing newspapers, magazines, periodicals, and books,  
24          but not including medical databases or court  
25          records) that include family medical history; or

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

4           (A) the employer provides written notice of  
5 the genetic monitoring to the employee;

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

8           (ii) the genetic monitoring is required by  
9 Federal or State law;

10          (C) the employee is informed of individual  
11 monitoring results;

12          (D) the monitoring is in compliance with—

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

22           (ii) State genetic monitoring regula-  
23 tions, in the case of a State that is imple-  
24 menting genetic monitoring regulations  
25 under the authority of the Occupational

1 Safety and Health Act of 1970 (29 U.S.C.  
2 651 et seq.); and

3 (E) the employer, excluding any licensed  
4 health care professional or board certified ge-  
5 netic counselor that is involved in the genetic  
6 monitoring program, receives the results of the  
7 monitoring only in aggregate terms that do not  
8 disclose the identity of specific employees;

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

15 **SEC. 203. EMPLOYMENT AGENCY PRACTICES.**

16 (a) USE OF GENETIC INFORMATION.—It shall be an  
17 unlawful employment practice for an employment agen-  
18 cy—

19 (1) to fail or refuse to refer for employment, or  
20 otherwise to discriminate against, any individual be-  
21 cause of genetic information with respect to the indi-  
22 vidual (or information about a request for or the re-  
23 ceipt of genetic services by such individual or family  
24 member of such individual);

1           (2) to limit, segregate, or classify individuals or  
2 fail or refuse to refer for employment any individual  
3 in any way that would deprive or tend to deprive any  
4 individual of employment opportunities, or otherwise  
5 adversely affect the status of the individual as an  
6 employee, because of genetic information with re-  
7 spect to the individual (or information about a re-  
8 quest for or the receipt of genetic services by such  
9 individual or family member of such individual); or  
10           (3) to cause or attempt to cause an employer to  
11 discriminate against an individual in violation of this  
12 title.

13           (b) ACQUISITION OF GENETIC INFORMATION.—It  
14 shall be an unlawful employment practice for an employ-  
15 ment agency to request, require, or purchase genetic infor-  
16 mation with respect to an individual or a family member  
17 of the individual (or information about a request for the  
18 receipt of genetic services by such individual or a family  
19 member of such individual) except—

20           (1) where an employment agency inadvertently  
21 requests or requires family medical history of the in-  
22 dividual or family member of the individual;

23           (2) where—

24           (A) health or genetic services are offered  
25 by the employment agency, including such serv-

1           ices offered as part of a bona fide wellness pro-  
2           gram;

3                 (B) the individual provides prior, knowing,  
4           voluntary, and written authorization;

5                 (C) only the individual (or family member  
6           if the family member is receiving genetic serv-  
7           ices) and the licensed health care professional  
8           or board certified genetic counselor involved in  
9           providing such services receive individually iden-  
10          tifiable information concerning the results of  
11          such services; and

12                (D) any individually identifiable genetic in-  
13          formation provided under subparagraph (C) in  
14          connection with the services provided under  
15          subparagraph (A) is only available for purposes  
16          of such services and shall not be disclosed to  
17          the employment agency except in aggregate  
18          terms that do not disclose the identity of spe-  
19          cific individuals;

20                (3) where an employment agency requests or re-  
21          quires family medical history from the individual to  
22          comply with the certification provisions of section  
23          103 of the Family and Medical Leave Act of 1993  
24          (29 U.S.C. 2613) or such requirements under State  
25          family and medical leave laws;

1           (4) where an employment agency purchases  
2 documents that are commercially and publicly avail-  
3 able (including newspapers, magazines, periodicals,  
4 and books, but not including medical databases or  
5 court records) that include family medical history; or

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

9           (A) the employment agency provides writ-  
10 ten notice of the genetic monitoring to the indi-  
11 vidual;

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

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

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

18           (D) the monitoring is in compliance with—

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



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

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

9 (E) the employment agency, excluding any  
10 licensed health care professional or board cer-  
11 tified genetic counselor that is involved in the  
12 genetic monitoring program, receives the results  
13 of the monitoring only in aggregate terms that  
14 do not disclose the identity of specific individ-  
15 uals;

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

22 **SEC. 204. LABOR ORGANIZATION PRACTICES.**

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

1           (1) to exclude or to expel from the membership  
2 of the organization, or otherwise to discriminate  
3 against, any member because of genetic information  
4 with respect to the member (or information about a  
5 request for or the receipt of genetic services by such  
6 member or family member of such member);

7           (2) to limit, segregate, or classify the members  
8 of the organization, or fail or refuse to refer for em-  
9 ployment any member, in any way that would de-  
10 prive or tend to deprive any member of employment  
11 opportunities, or otherwise adversely affect the sta-  
12 tus of the member as an employee, because of ge-  
13 netic information with respect to the member (or in-  
14 formation about a request for or the receipt of ge-  
15 netic services by such member or family member of  
16 such member); or

17           (3) to cause or attempt to cause an employer to  
18 discriminate against a member in violation of this  
19 title.

20       (b) ACQUISITION OF GENETIC INFORMATION.—It  
21 shall be an unlawful employment practice for a labor orga-  
22 nization to request, require, or purchase genetic informa-  
23 tion with respect to a member or a family member of the  
24 member (or information about a request for the receipt

1 of genetic services by such member or a family member  
2 of such member) except—

3 (1) where a labor organization inadvertently re-  
4 quests or requires family medical history of the  
5 member or family member of the member;

6 (2) where—

7 (A) health or genetic services are offered  
8 by the labor organization, including such serv-  
9 ices offered as part of a bona fide wellness pro-  
10 gram;

11 (B) the member provides prior, knowing,  
12 voluntary, and written authorization;

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

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

1 terms that do not disclose the identity of spe-  
2 cific members;

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

9 (4) where a labor organization purchases docu-  
10 ments that are commercially and publicly available  
11 (including newspapers, magazines, periodicals, and  
12 books, 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 labor organization provides written  
18 notice of the genetic monitoring to the member;

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

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

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

22 (c) PRESERVATION OF PROTECTIONS.—In the case  
23 of information to which any of paragraphs (1) through  
24 (5) of subsection (b) applies, such information may not  
25 be used in violation of paragraph (1) or (2) of subsection

1 (a) or treated or disclosed in a manner that violates sec-  
2 tion 206.

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

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

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

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

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

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

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

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

19 (2) where—

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

1 (B) the individual provides prior, knowing,  
2 voluntary, and written authorization;

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

10 (D) any individually identifiable genetic in-  
11 formation provided under subparagraph (C) in  
12 connection with the services provided under  
13 subparagraph (A) is only available for purposes  
14 of such services and shall not be disclosed to  
15 the employer, labor organization, or joint labor-  
16 management committee except in aggregate  
17 terms that do not disclose the identity of spe-  
18 cific individuals;

19 (3) where the employer, labor organization, or  
20 joint labor-management committee requests or re-  
21 quires family medical history from the individual to  
22 comply with the certification provisions of section  
23 103 of the Family and Medical Leave Act of 1993  
24 (29 U.S.C. 2613) or such requirements under State  
25 family and medical leave laws;



1           (4) where the employer, labor organization, or  
2 joint labor-management committee purchases docu-  
3 ments that are commercially and publicly available  
4 (including newspapers, magazines, periodicals, and  
5 books, but not including medical databases or court  
6 records) that include family medical history; or

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

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

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

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

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

20           (D) the monitoring is in compliance with—

21           (i) any Federal genetic monitoring  
22 regulations, including any such regulations  
23 that may be promulgated by the Secretary  
24 of Labor pursuant to the Occupational  
25 Safety and Health Act of 1970 (29 U.S.C.

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

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

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

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

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

2 (a) TREATMENT OF INFORMATION AS PART OF CON-  
3 FIDENTIAL MEDICAL RECORD.—If an employer, employ-  
4 ment agency, labor organization, or joint labor-manage-  
5 ment committee possesses genetic information about an  
6 employee or member (or information about a request for  
7 or receipt of genetic services by such employee or member  
8 or family member of such employee or member), such in-  
9 formation shall be maintained on separate forms and in  
10 separate medical files and be treated as a confidential  
11 medical record of the employee or member.

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

19 (1) to the employee (or family member if the  
20 family member is receiving the genetic services) or  
21 member of a labor organization at the request of the  
22 employee or member of such organization;

23 (2) to an occupational or other health re-  
24 searcher if the research is conducted in compliance  
25 with the regulations and protections provided for

1 under part 46 of title 45, Code of Federal Regula-  
2 tions;

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

5 (A) the employer, employment agency,  
6 labor organization, or joint labor-management  
7 committee may disclose only the genetic infor-  
8 mation expressly authorized by such order; and

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

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

19 (5) to the extent that such disclosure is made  
20 in connection with the employee's compliance with  
21 the certification provisions of section 103 of the  
22 Family and Medical Leave Act of 1993 (29 U.S.C.  
23 2613) or such requirements under State family and  
24 medical leave laws.

1 **SEC. 207. REMEDIES AND ENFORCEMENT.**

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

4 (1) IN GENERAL.—The powers, remedies, and  
5 procedures provided in sections 705, 706, 707, 709,  
6 710, and 711 of the Civil Rights Act of 1964 (42  
7 U.S.C. 2000e–4 et seq.) to the Commission, the At-  
8 torney General, or any person, alleging a violation of  
9 title VII of that Act (42 U.S.C. 2000e et seq.) shall  
10 be the powers, remedies, and procedures this title  
11 provides to the Commission, the Attorney General,  
12 or any person, respectively, alleging an unlawful em-  
13 ployment practice in violation of this title against an  
14 employee described in section 201(2)(A)(i), except as  
15 provided in paragraphs (2) and (3).

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

22 (3) DAMAGES.—The powers, remedies, and pro-  
23 cedures provided in section 1977A of the Revised  
24 Statutes (42 U.S.C. 1981a), including the limita-  
25 tions contained in subsection (b)(3) of such section  
26 1977A, shall be powers, remedies, and procedures

1 this title provides to the Commission, the Attorney  
2 General, or any person, alleging such a practice (not  
3 an employment practice specifically excluded from  
4 coverage under section 1977A(a)(1) of the Revised  
5 Statutes).

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

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

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

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

10          (c) EMPLOYEES COVERED BY CONGRESSIONAL AC-  
11          COUNTABILITY ACT OF 1995.—

12           (1) IN GENERAL.—The powers, remedies, and  
13           procedures provided in the Congressional Account-  
14           ability Act of 1995 (2 U.S.C. 1301 et seq.) to the  
15           Board (as defined in section 101 of that Act (2  
16           U.S.C. 1301)), or any person, alleging a violation of  
17           section 201(a)(1) of that Act (42 U.S.C. 1311(a)(1))  
18           shall be the powers, remedies, and procedures this  
19           title provides to that Board, or any person, alleging  
20           an unlawful employment practice in violation of this  
21           title against an employee described in section  
22           201(2)(A)(iii), 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 that Board, or any person, al-  
4 leging 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 that Board, or any person, al-  
11 leging such a practice (not an employment practice  
12 specifically excluded from coverage under section  
13 1977A(a)(1) of the Revised Statutes).

14 (4) OTHER APPLICABLE PROVISIONS.—With re-  
15 spect to a claim alleging a practice described in  
16 paragraph (1), title III of the Congressional Ac-  
17 countability Act of 1995 (2 U.S.C. 1381 et seq.)  
18 shall apply in the same manner as such title applies  
19 with respect to a claim alleging a violation of section  
20 201(a)(1) of such Act (2 U.S.C. 1311(a)(1)).

21 (d) EMPLOYEES COVERED BY CHAPTER 5 OF TITLE  
22 3, UNITED STATES CODE.—

23 (1) IN GENERAL.—The powers, remedies, and  
24 procedures provided in chapter 5 of title 3, United  
25 States Code, to the President, the Commission, the



1 Merit Systems Protection Board, or any person, al-  
2 leging a violation of section 411(a)(1) of that title,  
3 shall be the powers, remedies, and procedures this  
4 title provides to the President, the Commission, such  
5 Board, or any person, respectively, alleging an un-  
6 lawful employment practice in violation of this title  
7 against an employee described in section  
8 201(2)(A)(iv), except as provided in paragraphs (2)  
9 and (3).

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

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

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

3 (1) IN GENERAL.—The powers, remedies, and  
4 procedures provided in section 717 of the Civil  
5 Rights Act of 1964 (42 U.S.C. 2000e–16) to the  
6 Commission, the Attorney General, the Librarian of  
7 Congress, or any person, alleging a violation of that  
8 section shall be the powers, remedies, and proce-  
9 dures this title provides to the Commission, the At-  
10 torney General, the Librarian of Congress, or any  
11 person, respectively, alleging an unlawful employ-  
12 ment practice in violation of this title against an em-  
13 ployee or applicant described in section  
14 201(2)(A)(v), except as provided in paragraphs (2)  
15 and (3).

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

23 (3) DAMAGES.—The powers, remedies, and pro-  
24 cedures provided in section 1977A of the Revised  
25 Statutes (42 U.S.C. 1981a), including the limita-

1 tions contained in subsection (b)(3) of such section  
2 1977A, shall be powers, remedies, and procedures  
3 this title provides to the Commission, the Attorney  
4 General, the Librarian of Congress, or any person,  
5 alleging such a practice (not an employment practice  
6 specifically excluded from coverage under section  
7 1977A(a)(1) of the Revised Statutes).

8 (f) DEFINITION.—In this section, the term “Commis-  
9 sion” means the Equal Employment Opportunity Commis-  
10 sion.

11 **SEC. 208. DISPARATE IMPACT.**

12 (a) GENERAL RULE.—Notwithstanding any other  
13 provision of this Act, “disparate impact”, as that term is  
14 used in section 703(k) of the Civil Rights Act of 1964  
15 (42 U.S.C. 2000e–2(k)), on the basis of genetic informa-  
16 tion does not establish a cause of action under this Act.

17 (b) COMMISSION.—On the date that is 6 years after  
18 the date of enactment of this Act, there shall be estab-  
19 lished a commission, to be known as the Genetic Non-  
20 discrimination Study Commission (referred to in this sec-  
21 tion as the “Commission”) to review the developing  
22 science of genetics and to make recommendations to Con-  
23 gress regarding whether to provide a disparate impact  
24 cause of action under this Act.

25 (c) MEMBERSHIP.—

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

3           (A) 1 member shall be appointed by the  
4 Majority Leader of the Senate;

5           (B) 1 member shall be appointed by the  
6 Minority Leader of the Senate;

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

10          (D) 1 member shall be appointed by the  
11 ranking minority member of the Committee on  
12 Health, Education, Labor, and Pensions of the  
13 Senate;

14          (E) 1 member shall be appointed by the  
15 Speaker of the House of Representatives;

16          (F) 1 member shall be appointed by the  
17 Minority Leader of the House of Representa-  
18 tives;

19          (G) 1 member shall be appointed by the  
20 Chairman of the Committee on Education and  
21 the Workforce of the House of Representatives;  
22 and

23          (H) 1 member shall be appointed by the  
24 ranking minority member of the Committee on

1 Education and the Workforce of the House of  
2 Representatives.

3 (2) COMPENSATION AND EXPENSES.—The  
4 members of the Commission shall not receive com-  
5 pensation for the performance of services for the  
6 Commission, but shall be allowed travel expenses, in-  
7 cluding per diem in lieu of subsistence, at rates au-  
8 thorized for employees of agencies under subchapter  
9 I of chapter 57 of title 5, United States Code, while  
10 away from their homes or regular places of business  
11 in the performance of services for the Commission.

12 (d) ADMINISTRATIVE PROVISIONS.—

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

16 (2) DETAIL OF GOVERNMENT EMPLOYEES.—  
17 Any Federal Government employee may be detailed  
18 to the Commission without reimbursement, and such  
19 detail shall be without interruption or loss of civil  
20 service status or privilege.

21 (3) INFORMATION FROM FEDERAL AGENCIES.—  
22 The Commission may secure directly from any Fed-  
23 eral department or agency such information as the  
24 Commission considers necessary to carry out the  
25 provisions of this section. Upon request of the Com-

1 mission, the head of such department or agency  
2 shall furnish such information to the Commission.

3 (4) HEARINGS.—The Commission may hold  
4 such hearings, sit and act at such times and places,  
5 take such testimony, and receive such evidence as  
6 the Commission considers advisable to carry out the  
7 objectives of this section, except that, to the extent  
8 possible, the Commission shall use existing data and  
9 research.

10 (5) POSTAL SERVICES.—The Commission may  
11 use the United States mails in the same manner and  
12 under the same conditions as other departments and  
13 agencies of the Federal Government.

14 (e) REPORT.—Not later than 1 year after all of the  
15 members are appointed to the Commission under sub-  
16 section (c)(1), the Commission shall submit to Congress  
17 a report that summarizes the findings of the Commission  
18 and makes such recommendations for legislation as are  
19 consistent with this Act.

20 (f) AUTHORIZATION OF APPROPRIATIONS.—There  
21 are authorized to be appropriated to the Equal Employ-  
22 ment Opportunity Commission such sums as may be nec-  
23 essary to carry out this section.

24 **SEC. 209. CONSTRUCTION.**

25 Nothing in this title shall be construed to—

1           (1) limit the rights or protections of an indi-  
2           vidual under the Americans with Disabilities Act of  
3           1990 (42 U.S.C. 12101 et seq.), including coverage  
4           afforded to individuals under section 102 of such  
5           Act (42 U.S.C. 12112), or under the Rehabilitation  
6           Act of 1973 (29 U.S.C. 701 et seq.);

7           (2)(A) limit the rights or protections of an indi-  
8           vidual to bring an action under this title against an  
9           employer, employment agency, labor organization, or  
10          joint labor-management committee for a violation of  
11          this title; or

12          (B) establish a violation under this title for an  
13          employer, employment agency, labor organization, or  
14          joint labor-management committee of a provision of  
15          the amendments made by title I;

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

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

23          (5) limit or expand the protections, rights, or  
24          obligations of employees or employers under applica-  
25          ble workers' compensation laws;

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

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

12 **SEC. 210. MEDICAL INFORMATION THAT IS NOT GENETIC**  
13 **INFORMATION.**

14          An employer, employment agency, labor organization,  
15          or joint labor-management committee shall not be consid-  
16          ered to be in violation of this title based on the use, acqui-  
17          sition, or disclosure of medical information that is not ge-  
18          netic information about a manifested disease, disorder, or  
19          pathological condition of an employee or member, includ-  
20          ing a manifested disease, disorder, or pathological condi-  
21          tion that has or may have a genetic basis.

22 **SEC. 211. REGULATIONS.**

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



1 **SEC. 212. AUTHORIZATION OF APPROPRIATIONS.**

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

5 **SEC. 213. EFFECTIVE DATE.**

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

8       **TITLE III—MISCELLANEOUS**  
9                                   **PROVISION**

10 **SEC. 301. SEVERABILITY.**

11       If any provision of this Act, an amendment made by  
12 this Act, or the application of such provision or amend-  
13 ment to any person or circumstance is held to be unconsti-  
14 tutional, the remainder of this Act, the amendments made  
15 by this Act, and the application of such provisions to any  
16 person or circumstance shall not be affected thereby.

○