

109TH CONGRESS  
1ST SESSION

# S. 306

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## AN ACT

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

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

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

4       (a) **SHORT TITLE.**—This Act may be cited as the  
5 “Genetic Information Nondiscrimination Act of 2005”.

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

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

TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE

Sec. 101. Amendments to Employee Retirement Income Security Act of 1974.  
 Sec. 102. Amendments to the Public Health Service Act.  
 Sec. 103. Amendments to 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.

3 **SEC. 2. FINDINGS.**

4 Congress makes the following findings:

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

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

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17      have since been repealed, and many have been modi-  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

24           (3) Although genes are facially neutral markers,  
25      many genetic conditions and disorders are associated

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

18 (4) Congress has been informed of examples of  
19 genetic discrimination in the workplace. These in-  
20 clude the use of pre-employment genetic screening at  
21 Lawrence Berkeley Laboratory, which led to a court  
22 decision in favor of the employees in that case *Nor-*  
23 *man-Bloodsaw v. Lawrence Berkeley Laboratory* (135  
24 F.3d 1260, 1269 (9th Cir. 1998)). Congress clearly  
25 has a compelling public interest in relieving the fear

1 of discrimination and in prohibiting its actual prac-  
2 tice in employment and health insurance.

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

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

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

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

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

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

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

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

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

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

16          “(c) GENETIC TESTING.—

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

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

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

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

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

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

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



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

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

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

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

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

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

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

10 “(B) ADMINISTRATIVE PENALTY.—

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

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

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

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

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

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

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

14 “(B) AMOUNT.—

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

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

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

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

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

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

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

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

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

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

3                   “(D) LIMITATIONS.—

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

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

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

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

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

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

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

15 “(II) \$500,000.

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

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

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

3           “(A) the spouse of the individual;

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

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

10          “(6) GENETIC INFORMATION.—

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

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

15           “(ii) the genetic tests of family mem-  
16 bers of the individual; or

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

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

23          “(7) GENETIC TEST.—

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

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

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

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

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

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

18 “(A) a genetic test;

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

21 or

22 “(C) genetic education.”

23 (e) REGULATIONS AND EFFECTIVE DATE.—

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



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

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

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

10 **ACT.**

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

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

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

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

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

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

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

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

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

23 “(c) GENETIC TESTING.—

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

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

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

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

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

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

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

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

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

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

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

18 “(B) AMOUNT.—

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

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

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

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

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

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

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

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

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

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

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

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

6 “(D) LIMITATIONS.—

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

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

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

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

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

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

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

17 “(II) \$500,000.

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

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

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

6                   “(A) the spouse of the individual;

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

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

13           “(16) GENETIC INFORMATION.—

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

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

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

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

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



1           “(17) GENETIC TEST.—

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

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

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

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

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

21           “(A) a genetic test;

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

24           or

25           “(C) genetic education.”.

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

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

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

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

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

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

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

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

5 “(c) GENETIC TESTING.—

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

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

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

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

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

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

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

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

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

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

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

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

16 (d) REGULATIONS AND EFFECTIVE DATE.—

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

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

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

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

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

13 (a) NONDISCRIMINATION.—

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

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

1           netic services by such individual or family mem-  
2           ber of such individual).

3           “(ii) For purposes of clause (i), the terms  
4           ‘family member’, ‘genetic services’, and ‘genetic  
5           information’ shall have the meanings given such  
6           terms in subsection (x).”.

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

11         (b) LIMITATIONS ON GENETIC TESTING.—

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

15         “(x) LIMITATIONS ON GENETIC TESTING.—

16           “(1) GENETIC TESTING.—

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

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

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

1 care services with respect to an individual  
 2 to request that such individual or a family  
 3 member of such individual undergo a ge-  
 4 netic test;

5 “(ii) limit the authority of a health  
 6 care professional who is employed by or af-  
 7 filiated with an issuer of a medicare sup-  
 8 plemental policy and who is providing  
 9 health care services to an individual as  
 10 part of a bona fide wellness program to no-  
 11 tify such individual of the availability of a  
 12 genetic test or to provide information to  
 13 such individual regarding such genetic test;  
 14 or

15 “(iii) authorize or permit a health  
 16 care professional to require that an indi-  
 17 vidual undergo a genetic test.

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

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

21 “(i) the spouse of the individual;

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



1           “(iii) any other individuals related by  
2 blood to the individual or to the spouse or  
3 child described in clause (i) or (ii).

4           “(B) GENETIC INFORMATION.—

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

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

9           “(II) the genetic tests of family  
10 members of the individual; or

11           “(III) the occurrence of a disease  
12 or disorder in family members of the  
13 individual.

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

17           “(C) GENETIC TEST.—

18           “(i) IN GENERAL.—The term ‘genetic  
19 test’ means an analysis of human DNA,  
20 RNA, chromosomes, proteins, or metabo-  
21 lites, that detects genotypes, mutations, or  
22 chromosomal changes.

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

1           “(I) an analysis of proteins or  
2           metabolites that does not detect  
3           genotypes, mutations, or chromosomal  
4           changes; or

5           “(II) an analysis of proteins or  
6           metabolites that is directly related to  
7           a manifested disease, disorder, or  
8           pathological condition that could rea-  
9           sonably be detected by a health care  
10          professional with appropriate training  
11          and expertise in the field of medicine  
12          involved.

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

15           “(i) a genetic test;

16           “(ii) genetic counseling (such as ob-  
17          taining, interpreting, or assessing genetic  
18          information); or

19           “(iii) genetic education.

20           “(E) ISSUER OF A MEDICARE SUPPLE-  
21          MENTAL POLICY.—The term ‘issuer of a medi-  
22          care supplemental policy’ includes a third-party  
23          administrator or other person acting for or on  
24          behalf of such issuer.”.

1           (2) CONFORMING AMENDMENT.—Section  
2 1882(o) of the Social Security Act (42 U.S.C.  
3 1395ss(o)) is amended by adding at the end the fol-  
4 lowing:

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

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

13 (c) TRANSITION PROVISIONS.—

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

23           (2) NAIC STANDARDS.—If, not later than June  
24 30, 2006, the National Association of Insurance  
25 Commissioners (in this subsection referred to as the

1 “NAIC”) modifies its NAIC Model Regulation relat-  
2 ing to section 1882 of the Social Security Act (re-  
3 ferred to in such section as the 1991 NAIC Model  
4 Regulation, as subsequently modified) to conform to  
5 the amendments made by this section, such revised  
6 regulation incorporating the modifications shall be  
7 considered to be the applicable NAIC model regula-  
8 tion (including the revised NAIC model regulation  
9 and the 1991 NAIC Model Regulation) for the pur-  
10 poses of such section.

11 (3) SECRETARY STANDARDS.—If the NAIC  
12 does not make the modifications described in para-  
13 graph (2) within the period specified in such para-  
14 graph, the Secretary of Health and Human Services  
15 shall, not later than October 1, 2006, make the  
16 modifications described in such paragraph and such  
17 revised regulation incorporating the modifications  
18 shall be considered to be the appropriate regulation  
19 for the purposes of such section.

20 (4) DATE SPECIFIED.—

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

24 (i) the date the State changes its stat-  
25 utes or regulations to conform its regu-

1 latory program to the changes made by  
2 this section, or

3 (ii) October 1, 2006.

4 (B) ADDITIONAL LEGISLATIVE ACTION RE-  
5 QUIRED.—In the case of a State which the Sec-  
6 retary identifies as—

7 (i) requiring State legislation (other  
8 than legislation appropriating funds) to  
9 conform its regulatory program to the  
10 changes made in this section, but

11 (ii) having a legislature which is not  
12 scheduled to meet in 2006 in a legislative  
13 session in which such legislation may be  
14 considered, the date specified in this para-  
15 graph is the first day of the first calendar  
16 quarter beginning after the close of the  
17 first legislative session of the State legisla-  
18 ture that begins on or after July 1, 2006.  
19 For purposes of the previous sentence, in  
20 the case of a State that has a 2-year legis-  
21 lative session, each year of such session  
22 shall be deemed to be a separate regular  
23 session of the State legislature.

1 **SEC. 104. PRIVACY AND CONFIDENTIALITY.**

2 (a) APPLICABILITY.—Except as provided in sub-  
3 section (d), the provisions of this section shall apply to  
4 group health plans, health insurance issuers (including  
5 issuers in connection with group health plans or individual  
6 health coverage), and issuers of medicare supplemental  
7 policies, without regard to—

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

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

12 (3) section 9831(a)(2) of the Internal Revenue  
13 Code of 1986.

14 (b) COMPLIANCE WITH CERTAIN CONFIDENTIALITY  
15 STANDARDS WITH RESPECT TO GENETIC INFORMA-  
16 TION.—

17 (1) IN GENERAL.—The regulations promulgated  
18 by the Secretary of Health and Human Services  
19 under part C of title XI of the Social Security Act  
20 (42 U.S.C. 1320d et seq.) and section 264 of the  
21 Health Insurance Portability and Accountability Act  
22 of 1996 (42 U.S.C. 1320d–2 note) shall apply to the  
23 use or disclosure of genetic information.

24 (2) PROHIBITION ON UNDERWRITING AND PRE-  
25 MIUM RATING.—Notwithstanding paragraph (1), a  
26 group health plan, a health insurance issuer, or

1 issuer of a medicare supplemental policy shall not  
2 use or disclose genetic information (including infor-  
3 mation about a request for or a receipt of genetic  
4 services by an individual or family member of such  
5 individual) for purposes of underwriting, determina-  
6 tions of eligibility to enroll, premium rating, or the  
7 creation, renewal or replacement of a plan, contract  
8 or coverage for health insurance or health benefits.

9 (c) PROHIBITION ON COLLECTION OF GENETIC IN-  
10 FORMATION.—

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

21 (2) LIMITATION RELATING TO THE COLLEC-  
22 TION OF GENETIC INFORMATION PRIOR TO ENROLL-  
23 MENT.—A group health plan, health insurance  
24 issuer, or issuer of a medicare supplemental policy  
25 shall not request, require, or purchase genetic infor-

1 mation (including information about a request for or  
2 a receipt of genetic services by an individual or fam-  
3 ily member of such individual) concerning a partici-  
4 pant, beneficiary, or enrollee prior to the enrollment,  
5 and in connection with such enrollment, of such indi-  
6 vidual under the plan, coverage, or policy.

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

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

17 (B) any genetic information (including in-  
18 formation about a request for or receipt of ge-  
19 netic services) requested, required, or purchased  
20 is not used or disclosed in violation of sub-  
21 section (b).

22 (d) APPLICATION OF CONFIDENTIALITY STAND-  
23 ARDS.—The provisions of subsections (b) and (c) shall not  
24 apply—



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

9           (2) to genetic information that is not considered  
10          to be individually-identifiable health information  
11          under the regulations promulgated by the Secretary  
12          of Health and Human Services under part C of title  
13          XI of the Social Security Act (42 U.S.C. 1320d et  
14          seq.) and section 264 of the Health Insurance Port-  
15          ability and Accountability Act of 1996 (42 U.S.C.  
16          1320d–2 note).

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

25          (f) PREEMPTION.—

1           (1) IN GENERAL.—A provision or requirement  
2           under this section or a regulation promulgated under  
3           this section shall supersede any contrary provision of  
4           State law unless such provision of State law imposes  
5           requirements, standards, or implementation speci-  
6           fications that are more stringent than the require-  
7           ments, standards, or implementation specifications  
8           imposed under this section or such regulations. No  
9           penalty, remedy, or cause of action to enforce such  
10          a State law that is more stringent shall be pre-  
11          empted by this section.

12          (2) RULE OF CONSTRUCTION.—Nothing in  
13          paragraph (1) shall be construed to establish a pen-  
14          alty, remedy, or cause of action under State law if  
15          such penalty, remedy, or cause of action is not oth-  
16          erwise available under such State law.

17          (g) COORDINATION WITH PRIVACY REGULATIONS.—  
18          The Secretary shall implement and administer this section  
19          in a manner that is consistent with the implementation  
20          and administration by the Secretary of the regulations  
21          promulgated by the Secretary of Health and Human Serv-  
22          ices under part C of title XI of the Social Security Act  
23          (42 U.S.C. 1320d et seq.) and section 264 of the Health  
24          Insurance Portability and Accountability Act of 1996 (42  
25          U.S.C. 1320d–2 note).

1 (h) DEFINITIONS.—In this section:

2 (1) GENETIC INFORMATION; GENETIC SERV-  
3 ICES.—The terms “family member”, “genetic infor-  
4 mation”, “genetic services”, and “genetic test” have  
5 the meanings given such terms in section 2791 of  
6 the Public Health Service Act (42 U.S.C. 300gg-  
7 91), as amended by this Act.

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

13 (3) ISSUER OF A MEDICARE SUPPLEMENTAL  
14 POLICY.—The term “issuer of a medicare supple-  
15 mental policy” means an issuer described in section  
16 1882 of the Social Security Act (42 insert 1395ss).

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

19 **SEC. 105. ASSURING COORDINATION.**

20 (a) IN GENERAL.—Except as provided in subsection  
21 (b), the Secretary of the Treasury, the Secretary of Health  
22 and Human Services, and the Secretary of Labor shall en-  
23 sure, through the execution of an interagency memo-  
24 randum of understanding among such Secretaries, that—

1           (1) regulations, rulings, and interpretations  
2 issued by such Secretaries relating to the same mat-  
3 ter over which two or more such Secretaries have re-  
4 sponsibility under this title (and the amendments  
5 made by this title) are administered so as to have  
6 the same effect at all times; and

7           (2) coordination of policies relating to enforcing  
8 the same requirements through such Secretaries in  
9 order to have a coordinated enforcement strategy  
10 that avoids duplication of enforcement efforts and  
11 assigns priorities in enforcement.

12       (b) **AUTHORITY OF THE SECRETARY.**—The Secretary  
13 of Health and Human Services has the sole authority to  
14 promulgate regulations to implement section 104.

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

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

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

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

5 **SEC. 201. DEFINITIONS.**

6 In this title:

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

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

13 (A) IN GENERAL.—The term “employee”  
14 means—

15 (i) an employee (including an appli-  
16 cant), as defined in section 701(f) of the  
17 Civil Rights Act of 1964 (42 U.S.C.  
18 2000e(f));

19 (ii) a State employee (including an ap-  
20 plicant) described in section 304(a) of the  
21 Government Employee Rights Act of 1991  
22 (42 U.S.C. 2000e–16e(a));

23 (iii) a covered employee (including an  
24 applicant), as defined in section 101 of the

1 Congressional Accountability Act of 1995  
2 (2 U.S.C. 1301);

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

6 (v) an employee or applicant to which  
7 section 717(a) of the Civil Rights Act of  
8 1964 (42 U.S.C. 2000e–16(a)) applies.

9 (B) EMPLOYER.—The term “employer”  
10 means—

11 (i) an employer (as defined in section  
12 701(b) of the Civil Rights Act of 1964 (42  
13 U.S.C. 2000e(b));

14 (ii) an entity employing a State em-  
15 ployee described in section 304(a) of the  
16 Government Employee Rights Act of 1991;

17 (iii) an employing office, as defined in  
18 section 101 of the Congressional Account-  
19 ability Act of 1995;

20 (iv) an employing office, as defined in  
21 section 411(e) of title 3, United States  
22 Code; or

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

1           (C) EMPLOYMENT AGENCY; LABOR ORGA-  
2           NIZATION.—The terms “employment agency”  
3           and “labor organization” have the meanings  
4           given the terms in section 701 of the Civil  
5           Rights Act of 1964 (42 U.S.C. 2000e).

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

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

11           (A) the spouse of the individual;

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

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

18          (4) GENETIC INFORMATION.—

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

22           (i) an individual’s genetic tests;

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

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

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

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

16 (6) GENETIC SERVICES.—The term “genetic  
17 services” means—

18 (A) a genetic test;

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

21 or

22 (C) genetic education.

23 (7) GENETIC TEST.—

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



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

4 (B) EXCEPTION.—The term “genetic test”  
5 does not mean an analysis of proteins or me-  
6 tabolites that does not detect genotypes,  
7 mutations, or chromosomal changes.

8 **SEC. 202. EMPLOYER PRACTICES.**

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

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

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

1 services by such employee or family member of such  
2 employee).

3 (b) ACQUISITION OF GENETIC INFORMATION.—It  
4 shall be an unlawful employment practice for an employer  
5 to request, require, or purchase genetic information with  
6 respect to an employee or a family member of the em-  
7 ployee (or information about a request for the receipt of  
8 genetic services by such employee or a family member of  
9 such employee) except—

10 (1) where an employer inadvertently requests or  
11 requires family medical history of the employee or  
12 family member of the employee;

13 (2) where—

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

17 (B) the employee provides prior, knowing,  
18 voluntary, and written authorization;

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

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

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

14 (4) where an employer purchases documents  
15 that are commercially and publicly available (includ-  
16 ing newspapers, magazines, periodicals, and books,  
17 but not including medical databases or court  
18 records) that include family medical history; or

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

22 (A) the employer provides written notice of  
23 the genetic monitoring to the employee;

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

1           (ii) the genetic monitoring is required by  
2 Federal or State law;

3           (C) the employee is informed of individual  
4 monitoring results;

5           (D) the monitoring is in compliance with—

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

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

21           (E) the employer, excluding any licensed  
22 health care professional or board certified ge-  
23 netic counselor that is involved in the genetic  
24 monitoring program, receives the results of the

1 monitoring only in aggregate terms that do not  
2 disclose the identity of specific employees;

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

9 **SEC. 203. EMPLOYMENT AGENCY PRACTICES.**

10 (a) USE OF GENETIC INFORMATION.—It shall be an  
11 unlawful employment practice for an employment  
12 agency—

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

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

1       quest for or the receipt of genetic services by such  
2       individual or family member of such individual); or  
3               (3) to cause or attempt to cause an employer to  
4       discriminate against an individual in violation of this  
5       title.

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

13               (1) where an employment agency inadvertently  
14      requests or requires family medical history of the in-  
15      dividual or family member of the individual;

16               (2) where—

17                       (A) health or genetic services are offered  
18                       by the employment agency, including such serv-  
19                       ices offered as part of a bona fide wellness pro-  
20                       gram;

21                       (B) the individual provides prior, knowing,  
22                       voluntary, and written authorization;

23                       (C) only the individual (or family member  
24                       if the family member is receiving genetic serv-  
25                       ices) and the licensed health care professional

1 or board certified genetic counselor involved in  
2 providing such services receive individually iden-  
3 tifiable information concerning the results of  
4 such services; and

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

13 (3) where an employment agency requests or re-  
14 quires family medical history from the individual to  
15 comply with the certification provisions of section  
16 103 of the Family and Medical Leave Act of 1993  
17 (29 U.S.C. 2613) or such requirements under State  
18 family and medical leave laws;

19 (4) where an employment agency purchases  
20 documents that are commercially and publicly avail-  
21 able (including newspapers, magazines, periodicals,  
22 and books, but not including medical databases or  
23 court 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 employment agency provides writ-  
5 ten notice of the genetic monitoring to the indi-  
6 vidual;

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

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

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

13          (D) the monitoring is in compliance with—

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

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



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

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

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

17 **SEC. 204. LABOR ORGANIZATION PRACTICES.**

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

20 (1) to exclude or to expel from the membership  
21 of the organization, or otherwise to discriminate  
22 against, any member because of genetic information  
23 with respect to the member (or information about a  
24 request for or the receipt of genetic services by such  
25 member or family member of such member);

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

11           (3) to cause or attempt to cause an employer to  
12 discriminate against a member in violation of this  
13 title.

14       (b) ACQUISITION OF GENETIC INFORMATION.—It  
15 shall be an unlawful employment practice for a labor orga-  
16 nization to request, require, or purchase genetic informa-  
17 tion with respect to a member or a family member of the  
18 member (or information about a request for the receipt  
19 of genetic services by such member or a family member  
20 of such member) except—

21           (1) where a labor organization inadvertently re-  
22 quests or requires family medical history of the  
23 member or family member of the member;

24           (2) where—

1 (A) health or genetic services are offered  
2 by the labor organization, including such serv-  
3 ices offered as part of a bona fide wellness pro-  
4 gram;

5 (B) the member provides prior, knowing,  
6 voluntary, and written authorization;

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

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

22 (3) where a labor organization requests or re-  
23 quires family medical history from the members to  
24 comply with the certification provisions of section  
25 103 of the Family and Medical Leave Act of 1993

1 (29 U.S.C. 2613) or such requirements under State  
2 family and medical leave laws;

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

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

11 (A) the labor organization provides written  
12 notice of the genetic monitoring to the member;

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

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

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

19 (D) the monitoring is in compliance with—

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

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

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

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

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. 205. TRAINING PROGRAMS.**

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

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

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

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

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

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

9 (1) where the employer, labor organization, or  
10 joint labor-management committee inadvertently re-  
11 quests or requires family medical history of the indi-  
12 vidual or family member of the individual;

13 (2) where—

14 (A) health or genetic services are offered  
15 by the employer, labor organization, or joint  
16 labor-management committee, including such  
17 services offered as part of a bona fide wellness  
18 program;

19 (B) the individual provides prior, knowing,  
20 voluntary, and written authorization;

21 (C) only the individual (or family member  
22 if the family member is receiving genetic serv-  
23 ices) and the licensed health care professional  
24 or board certified genetic counselor involved in  
25 providing such services receive individually iden-

1           tifiable information concerning the results of  
2           such services;

3                   (D) any individually identifiable genetic in-  
4           formation provided under subparagraph (C) in  
5           connection with the services provided under  
6           subparagraph (A) is only available for purposes  
7           of such services and shall not be disclosed to  
8           the employer, labor organization, or joint labor-  
9           management committee except in aggregate  
10          terms that do not disclose the identity of spe-  
11          cific individuals;

12                   (3) where the employer, labor organization, or  
13          joint labor-management committee requests or re-  
14          quires family medical history from the individual to  
15          comply with the certification provisions of section  
16          103 of the Family and Medical Leave Act of 1993  
17          (29 U.S.C. 2613) or such requirements under State  
18          family and medical leave laws;

19                   (4) where the employer, labor organization, or  
20          joint labor-management committee purchases docu-  
21          ments that are commercially and publicly available  
22          (including newspapers, magazines, periodicals, and  
23          books, but not including medical databases or court  
24          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, labor organization, or  
5 joint labor-management committee provides  
6 written notice of the genetic monitoring to the  
7 individual;

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

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

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

14 (D) the monitoring is in compliance with—

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

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

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

5           (E) the employer, labor organization, or  
6           joint labor-management committee, excluding  
7           any licensed health care professional or board  
8           certified genetic counselor that is involved in  
9           the genetic monitoring program, receives the re-  
10          sults of the monitoring only in aggregate terms  
11          that do not disclose the identity of specific indi-  
12          viduals;

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

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

20          (a) TREATMENT OF INFORMATION AS PART OF CON-  
21          FIDENTIAL MEDICAL RECORD.—If an employer, employ-  
22          ment agency, labor organization, or joint labor-manage-  
23          ment committee possesses genetic information about an  
24          employee or member (or information about a request for  
25          or receipt of genetic services by such employee or member

1 or family member of such employee or member), such in-  
2 formation shall be maintained on separate forms and in  
3 separate medical files and be treated as a confidential  
4 medical record of the employee or member.

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

12 (1) to the employee (or family member if the  
13 family member is receiving the genetic services) or  
14 member of a labor organization at the request of the  
15 employee or member of such organization;

16 (2) to an occupational or other health re-  
17 searcher if the research is conducted in compliance  
18 with the regulations and protections provided for  
19 under part 46 of title 45, Code of Federal Regula-  
20 tions;

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

23 (A) the employer, employment agency,  
24 labor organization, or joint labor-management

1 committee may disclose only the genetic infor-  
2 mation expressly authorized by such order; and

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

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

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

19 **SEC. 207. REMEDIES AND ENFORCEMENT.**

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

22 (1) **IN GENERAL.—**The powers, remedies, and  
23 procedures provided in sections 705, 706, 707, 709,  
24 710, and 711 of the Civil Rights Act of 1964 (42  
25 U.S.C. 2000e–4 et seq.) to the Commission, the At-

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

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

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

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

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

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

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

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

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

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

19 (2) COSTS AND FEES.—The powers, remedies,  
20 and procedures provided in subsections (b) and (c)  
21 of section 722 of the Revised Statutes (42 U.S.C.  
22 1988), shall be powers, remedies, and procedures  
23 this title provides to that Board, or any person, al-  
24 leging 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 that Board, or any person, al-  
7           leging such a practice (not an employment practice  
8           specifically excluded from coverage under section  
9           1977A(a)(1) of the Revised Statutes).

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

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

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



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

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

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

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

24 (1) IN GENERAL.—The powers, remedies, and  
25 procedures provided in section 717 of the Civil

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

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

19 (3) DAMAGES.—The powers, remedies, and pro-  
20 cedures provided in section 1977A of the Revised  
21 Statutes (42 U.S.C. 1981a), including the limita-  
22 tions contained in subsection (b)(3) of such section  
23 1977A, shall be powers, remedies, and procedures  
24 this title provides to the Commission, the Attorney  
25 General, the Librarian of Congress, or any person,

1 alleging such a practice (not an employment practice  
2 specifically excluded from coverage under section  
3 1977A(a)(1) of the Revised Statutes).

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

7 **SEC. 208. DISPARATE IMPACT.**

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

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

21 (c) MEMBERSHIP.—

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

24 (A) 1 member shall be appointed by the  
25 Majority Leader of the Senate;

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

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

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

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

12 (F) 1 member shall be appointed by the  
13 Minority Leader of the House of Representa-  
14 tives;

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

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

23 (2) COMPENSATION AND EXPENSES.—The  
24 members of the Commission shall not receive com-  
25 pensation for the performance of services for the

1 Commission, but shall be allowed travel expenses, in-  
2 cluding per diem in lieu of subsistence, at rates au-  
3 thorized for employees of agencies under subchapter  
4 I of chapter 57 of title 5, United States Code, while  
5 away from their homes or regular places of business  
6 in the performance of services for the Commission.

7 (d) ADMINISTRATIVE PROVISIONS.—

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

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

16 (3) INFORMATION FROM FEDERAL AGENCIES.—  
17 The Commission may secure directly from any Fed-  
18 eral department or agency such information as the  
19 Commission considers necessary to carry out the  
20 provisions of this section. Upon request of the Com-  
21 mission, the head of such department or agency  
22 shall furnish such information to the Commission.

23 (4) HEARINGS.—The Commission may hold  
24 such hearings, sit and act at such times and places,  
25 take such testimony, and receive such evidence as

1 the Commission considers advisable to carry out the  
2 objectives of this section, except that, to the extent  
3 possible, the Commission shall use existing data and  
4 research.

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

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

15 (f) **AUTHORIZATION OF APPROPRIATIONS.**—There  
16 are authorized to be appropriated to the Equal Employ-  
17 ment Opportunity Commission such sums as may be nec-  
18 essary to carry out this section.

19 **SEC. 209. CONSTRUCTION.**

20 Nothing in this title shall be construed to—

21 (1) limit the rights or protections of an indi-  
22 vidual under the Americans with Disabilities Act of  
23 1990 (42 U.S.C. 12101 et seq.), including coverage  
24 afforded to individuals under section 102 of such

1 Act (42 U.S.C. 12112), or under the Rehabilitation  
2 Act of 1973 (29 U.S.C. 701 et seq.);

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

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

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

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

19 (5) limit or expand the protections, rights, or  
20 obligations of employees or employers under applica-  
21 ble workers' compensation laws;

22 (6) limit the authority of a Federal department  
23 or agency to conduct or sponsor occupational or  
24 other health research that is conducted in compli-  
25 ance with the regulations contained in part 46 of

1 title 45, Code of Federal Regulations (or any cor-  
 2 responding or similar regulation or rule); and

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

8 **SEC. 210. MEDICAL INFORMATION THAT IS NOT GENETIC**  
 9 **INFORMATION.**

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

18 **SEC. 211. REGULATIONS.**

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

22 **SEC. 212. AUTHORIZATION OF APPROPRIATIONS.**

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



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

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

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

6 **SEC. 301. SEVERABILITY.**

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

Passed the Senate February 17, 2005.

Attest:

*Secretary.*

109<sup>TH</sup> CONGRESS  
1<sup>ST</sup> SESSION

**S. 306**

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**AN ACT**

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