

***In the Senate of the United States,***

*April 24, 2008.*

*Resolved*, That the bill from the House of Representatives (H.R. 493) entitled “An Act to prohibit discrimination on the basis of genetic information with respect to health insurance and employment.”, do pass with the following

**AMENDMENT:**

Strike out all after the enacting clause and insert:

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

2       (a) *SHORT TITLE.*—*This Act may be cited as the “Ge-*  
3 *netic Information Nondiscrimination Act of 2008”.*

4       (b) *TABLE OF CONTENTS.*—*The table of contents of this*  
5 *Act is as follows:*

*Sec. 1. Short title; table of contents.*

*Sec. 2. Findings.*

***TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE***

*Sec. 101. Amendments to Employee Retirement Income Security Act of 1974.*

*Sec. 102. Amendments to the Public Health Service Act.*

*Sec. 103. Amendments to the Internal Revenue Code of 1986.*

*Sec. 104. Amendments to title XVIII of the Social Security Act relating to*  
*medigap.*

*Sec. 105. Privacy and confidentiality.*

*Sec. 106. Assuring coordination.*

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 PROVISIONS

*Sec. 301. Severability.*

*Sec. 302. Child labor protections.*

**1 SEC. 2. FINDINGS.**

2 *Congress makes the following findings:*

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

1           (2) *The early science of genetics became the basis*  
2 *of State laws that provided for the sterilization of*  
3 *persons having presumed genetic “defects” such as*  
4 *mental retardation, mental disease, epilepsy, blind-*  
5 *ness, and hearing loss, among other conditions. The*  
6 *first sterilization law was enacted in the State of In-*  
7 *diana in 1907. By 1981, a majority of States adopted*  
8 *sterilization laws to “correct” apparent genetic traits*  
9 *or tendencies. Many of these State laws have since*  
10 *been repealed, and many have been modified to in-*  
11 *clude essential constitutional requirements of due*  
12 *process and equal protection. However, the current ex-*  
13 *pllosion in the science of genetics, and the history of*  
14 *sterilization laws by the States based on early genetic*  
15 *science, compels Congressional action in this area.*

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

1 *Americans. Once again, State legislatures began to*  
2 *enact discriminatory laws in the area, and in the*  
3 *early 1970s began mandating genetic screening of all*  
4 *African Americans for sickle cell anemia, leading to*  
5 *discrimination and unnecessary fear. To alleviate*  
6 *some of this stigma, Congress in 1972 passed the Na-*  
7 *tional Sickle Cell Anemia Control Act, which with-*  
8 *holds Federal funding from States unless sickle cell*  
9 *testing is voluntary.*

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

20 (5) *Federal law addressing genetic discrimina-*  
21 *tion in health insurance and employment is incom-*  
22 *plete in both the scope and depth of its protections.*  
23 *Moreover, while many States have enacted some type*  
24 *of genetic non-discrimination law, these laws vary*  
25 *widely with respect to their approach, application,*

1     *and level of protection. Congress has collected substan-*  
 2     *tial evidence that the American public and the med-*  
 3     *ical community find the existing patchwork of State*  
 4     *and Federal laws to be confusing and inadequate to*  
 5     *protect them from discrimination. Therefore Federal*  
 6     *legislation establishing a national and uniform basic*  
 7     *standard is necessary to fully protect the public from*  
 8     *discrimination and allay their concerns about the po-*  
 9     *tential for discrimination, thereby allowing individ-*  
 10    *uals to take advantage of genetic testing, technologies,*  
 11    *research, and new therapies.*

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

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

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

21           *(1) in paragraph (2)(A), by inserting before the*  
 22           *semicolon the following: “except as provided in para-*  
 23           *graph (3)”;* and

24           *(2) by adding at the end the following:*

1           “(3) *NO GROUP-BASED DISCRIMINATION ON*  
2 *BASIS OF GENETIC INFORMATION.*—

3           “(A) *IN GENERAL.*—*For purposes of this*  
4 *section, a group health plan, and a health insur-*  
5 *ance issuer offering group health insurance cov-*  
6 *erage in connection with a group health plan,*  
7 *may not adjust premium or contribution*  
8 *amounts for the group covered under such plan*  
9 *on the basis of genetic information.*

10           “(B) *RULE OF CONSTRUCTION.*—*Nothing in*  
11 *subparagraph (A) or in paragraphs (1) and (2)*  
12 *of subsection (d) shall be construed to limit the*  
13 *ability of a health insurance issuer offering*  
14 *health insurance coverage in connection with a*  
15 *group health plan to increase the premium for*  
16 *an employer based on the manifestation of a dis-*  
17 *ease or disorder of an individual who is enrolled*  
18 *in the plan. In such case, the manifestation of a*  
19 *disease or disorder in one individual cannot also*  
20 *be used as genetic information about other group*  
21 *members and to further increase the premium for*  
22 *the employer.”.*

23           (b) *LIMITATIONS ON GENETIC TESTING; PROHIBITION*  
24 *ON COLLECTION OF GENETIC INFORMATION; APPLICATION*  
25 *TO ALL PLANS.*—*Section 702 of the Employee Retirement*

1 *Income Security Act of 1974 (29 U.S.C. 1182) is amended*  
2 *by adding at the end the following:*

3 “(c) *GENETIC TESTING.*—

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

10 “(2) *RULE OF CONSTRUCTION.*—*Paragraph (1)*  
11 *shall not be construed to limit the authority of a*  
12 *health care professional who is providing health care*  
13 *services to an individual to request that such indi-*  
14 *vidual undergo a genetic test.*

15 “(3) *RULE OF CONSTRUCTION REGARDING PAY-*  
16 *MENT.*—

17 “(A) *IN GENERAL.*—*Nothing in paragraph*  
18 *(1) shall be construed to preclude a group health*  
19 *plan, or a health insurance issuer offering health*  
20 *insurance coverage in connection with a group*  
21 *health plan, from obtaining and using the results*  
22 *of a genetic test in making a determination re-*  
23 *garding payment (as such term is defined for the*  
24 *purposes of applying the regulations promul-*  
25 *gated by the Secretary of Health and Human*

1           *Services under part C of title XI of the Social*  
2           *Security Act and section 264 of the Health In-*  
3           *surance Portability and Accountability Act of*  
4           *1996, as may be revised from time to time) con-*  
5           *sistent with subsection (a).*

6           “(B) *LIMITATION.*—*For purposes of sub-*  
7           *paragraph (A), a group health plan, or a health*  
8           *insurance issuer offering health insurance cov-*  
9           *erage in connection with a group health plan,*  
10           *may request only the minimum amount of infor-*  
11           *mation necessary to accomplish the intended*  
12           *purpose.*

13           “(4) *RESEARCH EXCEPTION.*—*Notwithstanding*  
14           *paragraph (1), a group health plan, or a health in-*  
15           *surance issuer offering health insurance coverage in*  
16           *connection with a group health plan, may request,*  
17           *but not require, that a participant or beneficiary un-*  
18           *dergo a genetic test if each of the following conditions*  
19           *is met:*

20           “(A) *The request is made, in writing, pur-*  
21           *suant to research that complies with part 46 of*  
22           *title 45, Code of Federal Regulations, or equiva-*  
23           *lent Federal regulations, and any applicable*  
24           *State or local law or regulations for the protec-*  
25           *tion of human subjects in research.*



1           “(B) *The plan or issuer clearly indicates to*  
2           *each participant or beneficiary, or in the case of*  
3           *a minor child, to the legal guardian of such ben-*  
4           *eficiary, to whom the request is made that—*

5                     “(i) *compliance with the request is vol-*  
6                     *untary; and*

7                     “(ii) *non-compliance will have no ef-*  
8                     *fect on enrollment status or premium or*  
9                     *contribution amounts.*

10           “(C) *No genetic information collected or ac-*  
11           *quired under this paragraph shall be used for*  
12           *underwriting purposes.*

13           “(D) *The plan or issuer notifies the Sec-*  
14           *retary in writing that the plan or issuer is con-*  
15           *ducting activities pursuant to the exception pro-*  
16           *vided for under this paragraph, including a de-*  
17           *scription of the activities conducted.*

18           “(E) *The plan or issuer complies with such*  
19           *other conditions as the Secretary may by regula-*  
20           *tion require for activities conducted under this*  
21           *paragraph.*

22           “(d) *PROHIBITION ON COLLECTION OF GENETIC IN-*  
23           *FORMATION.—*

24                     “(1) *IN GENERAL.—A group health plan, and a*  
25           *health insurance issuer offering health insurance cov-*

1 *erage in connection with a group health plan, shall*  
2 *not request, require, or purchase genetic information*  
3 *for underwriting purposes (as defined in section 733).*

4 “(2) *PROHIBITION ON COLLECTION OF GENETIC*  
5 *INFORMATION PRIOR TO ENROLLMENT.*—A group  
6 *health plan, and a health insurance issuer offering*  
7 *health insurance coverage in connection with a group*  
8 *health plan, shall not request, require, or purchase ge-*  
9 *netic information with respect to any individual*  
10 *prior to such individual’s enrollment under the plan*  
11 *or coverage in connection with such enrollment.*

12 “(3) *INCIDENTAL COLLECTION.*—If a group  
13 *health plan, or a health insurance issuer offering*  
14 *health insurance coverage in connection with a group*  
15 *health plan, obtains genetic information incidental to*  
16 *the requesting, requiring, or purchasing of other in-*  
17 *formation concerning any individual, such request,*  
18 *requirement, or purchase shall not be considered a*  
19 *violation of paragraph (2) if such request, require-*  
20 *ment, or purchase is not in violation of paragraph*  
21 *(1).*

22 “(e) *APPLICATION TO ALL PLANS.*—The provisions of  
23 *subsections (a)(1)(F), (b)(3), (c), and (d), and subsection*  
24 *(b)(1) and section 701 with respect to genetic information,*

1 *shall apply to group health plans and health insurance*  
2 *issuers without regard to section 732(a).”.*

3       (c) *APPLICATION TO GENETIC INFORMATION OF A*  
4 *FETUS OR EMBRYO.—Such section is further amended by*  
5 *adding at the end the following:*

6       “(f) *GENETIC INFORMATION OF A FETUS OR EM-*  
7 *BRYO.—Any reference in this part to genetic information*  
8 *concerning an individual or family member of an indi-*  
9 *vidual shall—*

10               “(1) *with respect to such an individual or family*  
11 *member of an individual who is a pregnant woman,*  
12 *include genetic information of any fetus carried by*  
13 *such pregnant woman; and*

14               “(2) *with respect to an individual or family*  
15 *member utilizing an assisted reproductive technology,*  
16 *include genetic information of any embryo legally*  
17 *held by the individual or family member.”.*

18       (d) *DEFINITIONS.—Section 733(d) of the Employee*  
19 *Retirement Income Security Act of 1974 (29 U.S.C.*  
20 *1191b(d)) is amended by adding at the end the following:*

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

23                       “(A) *a dependent (as such term is used for*  
24 *purposes of section 701(f)(2)) of such individual,*  
25 *and*

1           “(B) any other individual who is a first-de-  
2           gree, second-degree, third-degree, or fourth-degree  
3           relative of such individual or of an individual  
4           described in subparagraph (A).

5           “(6) *GENETIC INFORMATION*.—

6           “(A) *IN GENERAL*.—The term ‘genetic infor-  
7           mation’ means, with respect to any individual,  
8           information about—

9                   “(i) such individual’s genetic tests,

10                   “(ii) the genetic tests of family mem-  
11                   bers of such individual, and

12                   “(iii) the manifestation of a disease or  
13                   disorder in family members of such indi-  
14                   vidual.

15           “(B) *INCLUSION OF GENETIC SERVICES AND*  
16           *PARTICIPATION IN GENETIC RESEARCH*.—Such  
17           term includes, with respect to any individual,  
18           any request for, or receipt of, genetic services, or  
19           participation in clinical research which includes  
20           genetic services, by such individual or any fam-  
21           ily member of such individual.

22           “(C) *EXCLUSIONS*.—The term ‘genetic infor-  
23           mation’ shall not include information about the  
24           sex or age of any individual.

25           “(7) *GENETIC TEST*.—

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

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

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

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

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

19                   “(A) a genetic test;

20                   “(B) genetic counseling (including obtain-  
21                   ing, interpreting, or assessing genetic informa-  
22                   tion); or

23                   “(C) genetic education.

24           “(9) *UNDERWRITING PURPOSES.*—The term ‘un-  
25           derwriting purposes’ means, with respect to any

1 *group health plan, or health insurance coverage of-*  
2 *fered in connection with a group health plan—*

3 *“(A) rules for, or determination of, eligi-*  
4 *bility (including enrollment and continued eligi-*  
5 *bility) for benefits under the plan or coverage;*

6 *“(B) the computation of premium or con-*  
7 *tribution amounts under the plan or coverage;*

8 *“(C) the application of any pre-existing*  
9 *condition exclusion under the plan or coverage;*  
10 *and*

11 *“(D) other activities related to the creation,*  
12 *renewal, or replacement of a contract of health*  
13 *insurance or health benefits.”.*

14 *(e) ERISA ENFORCEMENT.—Section 502 of the Em-*  
15 *ployee Retirement Income Security Act of 1974 (29 U.S.C.*  
16 *1132) is amended—*

17 *(1) in subsection (a)(6), by striking “(7), or (8)”*  
18 *and inserting “(7), (8), or (9)”;*

19 *(2) in subsection (b)(3), by striking “The Sec-*  
20 *retary” and inserting “Except as provided in sub-*  
21 *sections (c)(9) and (a)(6) (with respect to collecting*  
22 *civil penalties under subsection (c)(9)), the Sec-*  
23 *retary”;* and

1           (3) in subsection (c), by redesignating paragraph  
2           (9) as paragraph (10), and by inserting after para-  
3           graph (8) the following new paragraph:

4           “(9) *SECRETARIAL ENFORCEMENT AUTHORITY*  
5           *RELATING TO USE OF GENETIC INFORMATION.*—

6           “(A) *GENERAL RULE.*—*The Secretary may*  
7           *impose a penalty against any plan sponsor of a*  
8           *group health plan, or any health insurance*  
9           *issuer offering health insurance coverage in con-*  
10           *nection with the plan, for any failure by such*  
11           *sponsor or issuer to meet the requirements of*  
12           *subsection (a)(1)(F), (b)(3), (c), or (d) of section*  
13           *702 or section 701 or 702(b)(1) with respect to*  
14           *genetic information, in connection with the plan.*

15           “(B) *AMOUNT.*—

16           “(i) *IN GENERAL.*—*The amount of the*  
17           *penalty imposed by subparagraph (A) shall*  
18           *be \$100 for each day in the noncompliance*  
19           *period with respect to each participant or*  
20           *beneficiary to whom such failure relates.*

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

1                   “(I) beginning on the date such  
2                   failure first occurs; and

3                   “(II) ending on the date the fail-  
4                   ure is corrected.

5                   “(C) *MINIMUM PENALTIES WHERE FAILURE*  
6                   *DISCOVERED.*—Notwithstanding clauses (i) and  
7                   (ii) of subparagraph (D):

8                   “(i) *IN GENERAL.*—In the case of 1 or  
9                   more failures with respect to a participant  
10                  or beneficiary—

11                  “(I) which are not corrected before  
12                  the date on which the plan receives a  
13                  notice from the Secretary of such viola-  
14                  tion; and

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

21                  “(ii) *HIGHER MINIMUM PENALTY*  
22                  *WHERE VIOLATIONS ARE MORE THAN DE*  
23                  *MINIMIS.*—To the extent violations for  
24                  which any person is liable under this para-  
25                  graph for any year are more than de mini-



1            *mis, clause (i) shall be applied by sub-*  
2            *stituting ‘\$15,000’ for ‘\$2,500’ with respect*  
3            *to such person.*

4            *“(D) LIMITATIONS.—*

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

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

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

22                            *“(II) such failure is corrected dur-*  
23                            *ing the 30-day period beginning on the*  
24                            *first date the person otherwise liable*  
25                            *for such penalty knew, or exercising*

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

3                   “(iii) *OVERALL LIMITATION FOR UNIN-*  
4                   *TENTIONAL FAILURES.—In the case of fail-*  
5                   *ures which are due to reasonable cause and*  
6                   *not to willful neglect, the penalty imposed*  
7                   *by subparagraph (A) for failures shall not*  
8                   *exceed the amount equal to the lesser of—*

9                                 “(I) *10 percent of the aggregate*  
10                                *amount paid or incurred by the plan*  
11                                *sponsor (or predecessor plan sponsor)*  
12                                *during the preceding taxable year for*  
13                                *group health plans; or*

14                                “(II) *\$500,000.*

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

22                   “(F) *DEFINITIONS.—Terms used in this*  
23                   *paragraph which are defined in section 733 shall*  
24                   *have the meanings provided such terms in such*  
25                   *section.”.*

1       (f) *REGULATIONS AND EFFECTIVE DATE.*—

2               (1) *REGULATIONS.*—*The Secretary of Labor shall*  
 3 *issue final regulations not later than 12 months after*  
 4 *the date of enactment of this Act to carry out the*  
 5 *amendments made by this section.*

6               (2) *EFFECTIVE DATE.*—*The amendments made*  
 7 *by this section shall apply with respect to group*  
 8 *health plans for plan years beginning after the date*  
 9 *that is 1 year after the date of enactment of this Act.*

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

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

14               (1) *NO DISCRIMINATION IN GROUP PREMIUMS*  
 15 *BASED ON GENETIC INFORMATION.*—*Section 2702(b)*  
 16 *of the Public Health Service Act (42 U.S.C. 300gg-*  
 17 *1(b)) is amended—*

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

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

22                               “(3) *NO GROUP-BASED DISCRIMINATION ON*  
 23 *BASIS OF GENETIC INFORMATION.*—

24                                       “(A) *IN GENERAL.*—*For purposes of this*  
 25 *section, a group health plan, and health insur-*

1           *ance issuer offering group health insurance cov-*  
2           *erage in connection with a group health plan,*  
3           *may not adjust premium or contribution*  
4           *amounts for the group covered under such plan*  
5           *on the basis of genetic information.*

6           “(B) *RULE OF CONSTRUCTION.*—*Nothing in*  
7           *subparagraph (A) or in paragraphs (1) and (2)*  
8           *of subsection (d) shall be construed to limit the*  
9           *ability of a health insurance issuer offering*  
10           *health insurance coverage in connection with a*  
11           *group health plan to increase the premium for*  
12           *an employer based on the manifestation of a dis-*  
13           *ease or disorder of an individual who is enrolled*  
14           *in the plan. In such case, the manifestation of a*  
15           *disease or disorder in one individual cannot also*  
16           *be used as genetic information about other group*  
17           *members and to further increase the premium for*  
18           *the employer.”.*

19           (2) *LIMITATIONS ON GENETIC TESTING; PROHIBI-*  
20           *TION ON COLLECTION OF GENETIC INFORMATION; AP-*  
21           *PLICATION TO ALL PLANS.*—*Section 2702 of the Pub-*  
22           *lic Health Service Act (42 U.S.C. 300gg-1) is amend-*  
23           *ed by adding at the end the following:*

24           “(c) *GENETIC TESTING.*—

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

7           “(2) *RULE OF CONSTRUCTION.*—Paragraph (1)  
8           shall not be construed to limit the authority of a  
9           health care professional who is providing health care  
10          services to an individual to request that such indi-  
11          vidual undergo a genetic test.

12          “(3) *RULE OF CONSTRUCTION REGARDING PAY-*  
13          *MENT.*—

14                 “(A) *IN GENERAL.*—Nothing in paragraph  
15                 (1) shall be construed to preclude a group health  
16                 plan, or a health insurance issuer offering health  
17                 insurance coverage in connection with a group  
18                 health plan, from obtaining and using the results  
19                 of a genetic test in making a determination re-  
20                 garding payment (as such term is defined for the  
21                 purposes of applying the regulations promul-  
22                 gated by the Secretary under part C of title XI  
23                 of the Social Security Act and section 264 of the  
24                 Health Insurance Portability and Accountability

1           *Act of 1996, as may be revised from time to*  
2           *time) consistent with subsection (a).*

3           “(B) *LIMITATION.—For purposes of sub-*  
4           *paragraph (A), a group health plan, or a health*  
5           *insurance issuer offering health insurance cov-*  
6           *erage in connection with a group health plan,*  
7           *may request only the minimum amount of infor-*  
8           *mation necessary to accomplish the intended*  
9           *purpose.*

10          “(4) *RESEARCH EXCEPTION.—Notwithstanding*  
11          *paragraph (1), a group health plan, or a health in-*  
12          *surance issuer offering health insurance coverage in*  
13          *connection with a group health plan, may request,*  
14          *but not require, that a participant or beneficiary un-*  
15          *dergo a genetic test if each of the following conditions*  
16          *is met:*

17               “(A) *The request is made pursuant to re-*  
18               *search that complies with part 46 of title 45,*  
19               *Code of Federal Regulations, or equivalent Fed-*  
20               *eral regulations, and any applicable State or*  
21               *local law or regulations for the protection of*  
22               *human subjects in research.*

23               “(B) *The plan or issuer clearly indicates to*  
24               *each participant or beneficiary, or in the case of*

1           *a minor child, to the legal guardian of such ben-*  
2           *eficiary, to whom the request is made that—*

3                     *“(i) compliance with the request is vol-*  
4                     *untary; and*

5                     *“(ii) non-compliance will have no ef-*  
6                     *fect on enrollment status or premium or*  
7                     *contribution amounts.*

8                     *“(C) No genetic information collected or ac-*  
9                     *quired under this paragraph shall be used for*  
10                    *underwriting purposes.*

11                    *“(D) The plan or issuer notifies the Sec-*  
12                    *retary in writing that the plan or issuer is con-*  
13                    *ducting activities pursuant to the exception pro-*  
14                    *vided for under this paragraph, including a de-*  
15                    *scription of the activities conducted.*

16                    *“(E) The plan or issuer complies with such*  
17                    *other conditions as the Secretary may by regula-*  
18                    *tion require for activities conducted under this*  
19                    *paragraph.*

20            *“(d) PROHIBITION ON COLLECTION OF GENETIC IN-*  
21            *FORMATION.—*

22                    *“(1) IN GENERAL.—A group health plan, and a*  
23                    *health insurance issuer offering health insurance cov-*  
24                    *erage in connection with a group health plan, shall*  
25                    *not request, require, or purchase genetic information*

1 *for underwriting purposes (as defined in section*  
2 *2791).*

3 “(2) *PROHIBITION ON COLLECTION OF GENETIC*  
4 *INFORMATION PRIOR TO ENROLLMENT.*—A group  
5 *health plan, and a health insurance issuer offering*  
6 *health insurance coverage in connection with a group*  
7 *health plan, shall not request, require, or purchase ge-*  
8 *netic information with respect to any individual*  
9 *prior to such individual’s enrollment under the plan*  
10 *or coverage in connection with such enrollment.*

11 “(3) *INCIDENTAL COLLECTION.*—If a group  
12 *health plan, or a health insurance issuer offering*  
13 *health insurance coverage in connection with a group*  
14 *health plan, obtains genetic information incidental to*  
15 *the requesting, requiring, or purchasing of other in-*  
16 *formation concerning any individual, such request,*  
17 *requirement, or purchase shall not be considered a*  
18 *violation of paragraph (2) if such request, require-*  
19 *ment, or purchase is not in violation of paragraph*  
20 *(1).*

21 “(e) *APPLICATION TO ALL PLANS.*—The provisions of  
22 *subsections (a)(1)(F), (b)(3), (c), and (d) and subsection*  
23 *(b)(1) and section 2701 with respect to genetic information,*  
24 *shall apply to group health plans and health insurance*  
25 *issuers without regard to section 2721(a).”*



1           (3) *APPLICATION TO GENETIC INFORMATION OF A*  
2           *FETUS OR EMBRYO.*—*Such section is further amended*  
3           *by adding at the end the following:*

4           “(f) *GENETIC INFORMATION OF A FETUS OR EM-*  
5           *BRYO.*—*Any reference in this part to genetic information*  
6           *concerning an individual or family member of an indi-*  
7           *vidual shall—*

8           “(1) *with respect to such an individual or family*  
9           *member of an individual who is a pregnant woman,*  
10           *include genetic information of any fetus carried by*  
11           *such pregnant woman; and*

12           “(2) *with respect to an individual or family*  
13           *member utilizing an assisted reproductive technology,*  
14           *include genetic information of any embryo legally*  
15           *held by the individual or family member.”.*

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

19           “(15) *FAMILY MEMBER.*—*The term ‘family mem-*  
20           *ber’ means, with respect to any individual—*

21           “(A) *a dependent (as such term is used for*  
22           *purposes of section 2701(f)(2)) of such indi-*  
23           *vidual; and*

24           “(B) *any other individual who is a first-de-*  
25           *gree, second-degree, third-degree, or fourth-degree*

1           *relative of such individual or of an individual*  
2           *described in subparagraph (A).*

3           “(16) *GENETIC INFORMATION.*—

4                   “(A) *IN GENERAL.*—*The term ‘genetic infor-*  
5                   *mation’ means, with respect to any individual,*  
6                   *information about—*

7                           “(i) *such individual’s genetic tests,*

8                           “(ii) *the genetic tests of family mem-*  
9                           *bers of such individual, and*

10                           “(iii) *the manifestation of a disease or*  
11                           *disorder in family members of such indi-*  
12                           *vidual.*

13                   “(B) *INCLUSION OF GENETIC SERVICES AND*  
14                   *PARTICIPATION IN GENETIC RESEARCH.*—*Such*  
15                   *term includes, with respect to any individual,*  
16                   *any request for, or receipt of, genetic services, or*  
17                   *participation in clinical research which includes*  
18                   *genetic services, by such individual or any fam-*  
19                   *ily member of such individual.*

20                   “(C) *EXCLUSIONS.*—*The term ‘genetic infor-*  
21                   *mation’ shall not include information about the*  
22                   *sex or age of any individual.*

23           “(17) *GENETIC TEST.*—

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

1            *mosomes, proteins, or metabolites, that detects*  
2            *genotypes, mutations, or chromosomal changes.*

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

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

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

15           “(18) *GENETIC SERVICES.*—*The term ‘genetic*  
16           *services’ means—*

17           “(A) *a genetic test;*

18           “(B) *genetic counseling (including obtain-*  
19           *ing, interpreting, or assessing genetic informa-*  
20           *tion); or*

21           “(C) *genetic education.*

22           “(19) *UNDERWRITING PURPOSES.*—*The term*  
23           *‘underwriting purposes’ means, with respect to any*  
24           *group health plan, or health insurance coverage of-*  
25           *fered in connection with a group health plan—*

1           “(A) rules for, or determination of, eligi-  
2           *bility (including enrollment and continued eligi-*  
3           *bility) for benefits under the plan or coverage;*

4           “(B) the computation of premium or con-  
5           *tribution amounts under the plan or coverage;*

6           “(C) the application of any pre-existing  
7           *condition exclusion under the plan or coverage;*  
8           *and*

9           “(D) other activities related to the creation,  
10          *renewal, or replacement of a contract of health*  
11          *insurance or health benefits.”.*

12          (5) *REMEDIES AND ENFORCEMENT.*—Section  
13          2722(b) of the Public Health Service Act (42 U.S.C.  
14          300gg–22(b)) is amended by adding at the end the fol-  
15          *lowing:*

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

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

1            *subsection (a)(1)(F), (b)(3), (c), or (d) of section*  
2            *2702 or section 2701 or 2702(b)(1) with respect*  
3            *to genetic information in connection with the*  
4            *plan.*

5            *“(B) AMOUNT.—*

6                    *“(i) IN GENERAL.—The amount of the*  
7                    *penalty imposed under this paragraph shall*  
8                    *be \$100 for each day in the noncompliance*  
9                    *period with respect to each participant or*  
10                   *beneficiary to whom such failure relates.*

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

15                            *“(I) beginning on the date such*  
16                            *failure first occurs; and*

17                            *“(II) ending on the date the fail-*  
18                            *ure is corrected.*

19            *“(C) MINIMUM PENALTIES WHERE FAILURE*  
20            *DISCOVERED.—Notwithstanding clauses (i) and*  
21            *(ii) of subparagraph (D):*

22                    *“(i) IN GENERAL.—In the case of 1 or*  
23                    *more failures with respect to an*  
24                    *individual—*

1                   “(I) which are not corrected before  
2                   the date on which the plan receives a  
3                   notice from the Secretary of such viola-  
4                   tion; and

5                   “(II) which occurred or continued  
6                   during the period involved;  
7                   the amount of penalty imposed by subpara-  
8                   graph (A) by reason of such failures with  
9                   respect to such individual shall not be less  
10                  than \$2,500.

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

19                  “(D) *LIMITATIONS.—*

20                  “(i) *PENALTY NOT TO APPLY WHERE*  
21                  *FAILURE NOT DISCOVERED EXERCISING*  
22                  *REASONABLE DILIGENCE.—No penalty shall*  
23                  *be imposed by subparagraph (A) on any*  
24                  *failure during any period for which it is es-*  
25                  *tablished to the satisfaction of the Secretary*

1           *that the person otherwise liable for such*  
2           *penalty did not know, and exercising rea-*  
3           *sonable diligence would not have known,*  
4           *that such failure existed.*

5           “(ii) *PENALTY NOT TO APPLY TO FAIL-*  
6           *URES CORRECTED WITHIN CERTAIN PERI-*  
7           *ODS.—No penalty shall be imposed by sub-*  
8           *paragraph (A) on any failure if—*

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

12                   “(II) *such failure is corrected dur-*  
13                    *ing the 30-day period beginning on the*  
14                    *first date the person otherwise liable*  
15                    *for such penalty knew, or exercising*  
16                    *reasonable diligence would have known,*  
17                    *that such failure existed.*

18           “(iii) *OVERALL LIMITATION FOR UNIN-*  
19            *TENTIONAL FAILURES.—In the case of fail-*  
20            *ures which are due to reasonable cause and*  
21            *not to willful neglect, the penalty imposed*  
22            *by subparagraph (A) for failures shall not*  
23            *exceed the amount equal to the lesser of—*

24                    “(I) *10 percent of the aggregate*  
25                    *amount paid or incurred by the em-*

1                    *ployer (or predecessor employer) dur-*  
 2                    *ing the preceding taxable year for*  
 3                    *group health plans; or*

4                    *“(II) \$500,000.*

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

12                    *(b) AMENDMENT RELATING TO THE INDIVIDUAL MAR-*  
 13                    *KET.—*

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

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

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

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

23                    *“(a) PROHIBITION ON GENETIC INFORMATION AS A*  
 24                    *CONDITION OF ELIGIBILITY.—*



1           “(1) *IN GENERAL.*—A health insurance issuer of-  
2           fering health insurance coverage in the individual  
3           market may not establish rules for the eligibility (in-  
4           cluding continued eligibility) of any individual to en-  
5           roll in individual health insurance coverage based on  
6           genetic information.

7           “(2) *RULE OF CONSTRUCTION.*—Nothing in  
8           paragraph (1) or in paragraphs (1) and (2) of sub-  
9           section (e) shall be construed to preclude a health in-  
10          surance issuer from establishing rules for eligibility  
11          for an individual to enroll in individual health insur-  
12          ance coverage based on the manifestation of a disease  
13          or disorder in that individual, or in a family member  
14          of such individual where such family member is cov-  
15          ered under the policy that covers such individual.

16          “(b) *PROHIBITION ON GENETIC INFORMATION IN SET-*  
17 *TING PREMIUM RATES.*—

18           “(1) *IN GENERAL.*—A health insurance issuer of-  
19           fering health insurance coverage in the individual  
20           market shall not adjust premium or contribution  
21           amounts for an individual on the basis of genetic in-  
22           formation concerning the individual or a family  
23           member of the individual.

24           “(2) *RULE OF CONSTRUCTION.*—Nothing in  
25           paragraph (1) or in paragraphs (1) and (2) of sub-

1 *section (e) shall be construed to preclude a health in-*  
2 *surance issuer from adjusting premium or contribu-*  
3 *tion amounts for an individual on the basis of a*  
4 *manifestation of a disease or disorder in that indi-*  
5 *vidual, or in a family member of such individual*  
6 *where such family member is covered under the policy*  
7 *that covers such individual. In such case, the mani-*  
8 *festation of a disease or disorder in one individual*  
9 *cannot also be used as genetic information about*  
10 *other individuals covered under the policy issued to*  
11 *such individual and to further increase premiums or*  
12 *contribution amounts.*

13 *“(c) PROHIBITION ON GENETIC INFORMATION AS PRE-*  
14 *EXISTING CONDITION.—*

15 *“(1) IN GENERAL.—A health insurance issuer of-*  
16 *fering health insurance coverage in the individual*  
17 *market may not, on the basis of genetic information,*  
18 *impose any preexisting condition exclusion (as de-*  
19 *fined in section 2701(b)(1)(A)) with respect to such*  
20 *coverage.*

21 *“(2) RULE OF CONSTRUCTION.—Nothing in*  
22 *paragraph (1) or in paragraphs (1) and (2) of sub-*  
23 *section (e) shall be construed to preclude a health in-*  
24 *surance issuer from imposing any preexisting condi-*  
25 *tion exclusion for an individual with respect to health*

1     *insurance coverage on the basis of a manifestation of*  
2     *a disease or disorder in that individual.*

3     “(d) *GENETIC TESTING.*—

4             “(1) *LIMITATION ON REQUESTING OR REQUIRING*  
5     *GENETIC TESTING.*—*A health insurance issuer offer-*  
6     *ing health insurance coverage in the individual mar-*  
7     *ket shall not request or require an individual or a*  
8     *family member of such individual to undergo a ge-*  
9     *netic test.*

10            “(2) *RULE OF CONSTRUCTION.*—*Paragraph (1)*  
11     *shall not be construed to limit the authority of a*  
12     *health care professional who is providing health care*  
13     *services to an individual to request that such indi-*  
14     *vidual undergo a genetic test.*

15            “(3) *RULE OF CONSTRUCTION REGARDING PAY-*  
16     *MENT.*—

17            “(A) *IN GENERAL.*—*Nothing in paragraph*  
18     *(1) shall be construed to preclude a health insur-*  
19     *ance issuer offering health insurance coverage in*  
20     *the individual market from obtaining and using*  
21     *the results of a genetic test in making a deter-*  
22     *mination regarding payment (as such term is*  
23     *defined for the purposes of applying the regula-*  
24     *tions promulgated by the Secretary under part C*  
25     *of title XI of the Social Security Act and section*

1           *264 of the Health Insurance Portability and Ac-*  
2           *countability Act of 1996, as may be revised from*  
3           *time to time) consistent with subsection (a) and*  
4           *(c).*

5           “(B) *LIMITATION.*—*For purposes of sub-*  
6           *paragraph (A), a health insurance issuer offering*  
7           *health insurance coverage in the individual mar-*  
8           *ket may request only the minimum amount of*  
9           *information necessary to accomplish the intended*  
10          *purpose.*

11          “(4) *RESEARCH EXCEPTION.*—*Notwithstanding*  
12          *paragraph (1), a health insurance issuer offering*  
13          *health insurance coverage in the individual market*  
14          *may request, but not require, that an individual or*  
15          *a family member of such individual undergo a genetic*  
16          *test if each of the following conditions is met:*

17               “(A) *The request is made pursuant to re-*  
18               *search that complies with part 46 of title 45,*  
19               *Code of Federal Regulations, or equivalent Fed-*  
20               *eral regulations, and any applicable State or*  
21               *local law or regulations for the protection of*  
22               *human subjects in research.*

23               “(B) *The issuer clearly indicates to each in-*  
24               *dividual, or in the case of a minor child, to the*

1           *legal guardian of such child, to whom the request*  
2           *is made that—*

3                     “(i) *compliance with the request is vol-*  
4                     *untary; and*

5                     “(ii) *non-compliance will have no ef-*  
6                     *fect on enrollment status or premium or*  
7                     *contribution amounts.*

8                     “(C) *No genetic information collected or ac-*  
9                     *quired under this paragraph shall be used for*  
10                    *underwriting purposes.*

11                    “(D) *The issuer notifies the Secretary in*  
12                    *writing that the issuer is conducting activities*  
13                    *pursuant to the exception provided for under this*  
14                    *paragraph, including a description of the activi-*  
15                    *ties conducted.*

16                    “(E) *The issuer complies with such other*  
17                    *conditions as the Secretary may by regulation*  
18                    *require for activities conducted under this para-*  
19                    *graph.*

20            “(e) *PROHIBITION ON COLLECTION OF GENETIC IN-*  
21            *FORMATION.—*

22                    “(1) *IN GENERAL.—A health insurance issuer of-*  
23                    *fering health insurance coverage in the individual*  
24                    *market shall not request, require, or purchase genetic*

1        *information for underwriting purposes (as defined in*  
2        *section 2791).*

3                “(2) *PROHIBITION ON COLLECTION OF GENETIC*  
4        *INFORMATION PRIOR TO ENROLLMENT.—A health in-*  
5        *surance issuer offering health insurance coverage in*  
6        *the individual market shall not request, require, or*  
7        *purchase genetic information with respect to any in-*  
8        *dividual prior to such individual’s enrollment under*  
9        *the plan in connection with such enrollment.*

10               “(3) *INCIDENTAL COLLECTION.—If a health in-*  
11        *surance issuer offering health insurance coverage in*  
12        *the individual market obtains genetic information in-*  
13        *cidental to the requesting, requiring, or purchasing of*  
14        *other information concerning any individual, such re-*  
15        *quest, requirement, or purchase shall not be consid-*  
16        *ered a violation of paragraph (2) if such request, re-*  
17        *quirement, or purchase is not in violation of para-*  
18        *graph (1).*

19               “(f) *GENETIC INFORMATION OF A FETUS OR EM-*  
20        *BRYO.—Any reference in this part to genetic information*  
21        *concerning an individual or family member of an indi-*  
22        *vidual shall—*

23               “(1) *with respect to such an individual or family*  
24        *member of an individual who is a pregnant woman,*

1       *include genetic information of any fetus carried by*  
2       *such pregnant woman; and*

3               “(2) *with respect to an individual or family*  
4       *member utilizing an assisted reproductive technology,*  
5       *include genetic information of any embryo legally*  
6       *held by the individual or family member.”.*

7               (2) *REMEDIES AND ENFORCEMENT.*—*Section*  
8       *2761(b) of the Public Health Service Act (42 U.S.C.*  
9       *300gg–61(b)) is amended to read as follows:*

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

20               (c) *ELIMINATION OF OPTION OF NON-FEDERAL GOV-*  
21       *ERNMENTAL PLANS TO BE EXCEPTED FROM REQUIRE-*  
22       *MENTS CONCERNING GENETIC INFORMATION.*—*Section*  
23       *2721(b)(2) of the Public Health Service Act (42 U.S.C.*  
24       *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 pro-*  
9 *visions of subsections (a)(1)(F), (b)(3), (c), and*  
10 *(d) of section 2702 and the provisions of sections*  
11 *2701 and 2702(b) to the extent that such provi-*  
12 *sions apply to genetic information.”.*

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

14           (1) *REGULATIONS.—Not later than 12 months*  
15 *after the date of enactment of this Act, the Secretary*  
16 *of Health and Human Services shall issue final regu-*  
17 *lations to carry out the amendments made by this sec-*  
18 *tion.*

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

21                   (A) *with respect to group health plans, and*  
22 *health insurance coverage offered in connection*  
23 *with group health plans, for plan years begin-*  
24 *ning after the date that is 1 year after the date*  
25 *of enactment of this Act; and*



1           (B) with respect to health insurance cov-  
 2           erage offered, sold, issued, renewed, in effect, or  
 3           operated in the individual market after the date  
 4           that is 1 year after the date of enactment of this  
 5           Act.

6 **SEC. 103. AMENDMENTS TO THE INTERNAL REVENUE CODE**  
 7           **OF 1986.**

8           (a) *NO DISCRIMINATION IN GROUP PREMIUMS BASED*  
 9 *ON GENETIC INFORMATION.*—Subsection (b) of section 9802  
 10 *of the Internal Revenue Code of 1986 is amended—*

11           (1) *in paragraph (2)(A), by inserting before the*  
 12 *semicolon the following: “except as provided in para-*  
 13 *graph (3)”*; and

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

15           “(3) *NO GROUP-BASED DISCRIMINATION ON*  
 16 *BASIS OF GENETIC INFORMATION.*—

17           “(A) *IN GENERAL.*—For purposes of this  
 18 *section, a group health plan may not adjust pre-*  
 19 *mium or contribution amounts for the group*  
 20 *covered under such plan on the basis of genetic*  
 21 *information.*

22           “(B) *RULE OF CONSTRUCTION.*—Nothing in  
 23 *subparagraph (A) or in paragraphs (1) and (2)*  
 24 *of subsection (d) shall be construed to limit the*  
 25 *ability of a group health plan to increase the*

1           *premium for an employer based on the mani-*  
2           *festation of a disease or disorder of an indi-*  
3           *vidual who is enrolled in the plan. In such case,*  
4           *the manifestation of a disease or disorder in one*  
5           *individual cannot also be used as genetic infor-*  
6           *mation about other group members and to fur-*  
7           *ther increase the premium for the employer.”.*

8           ***(b) LIMITATIONS ON GENETIC TESTING; PROHIBITION***  
9           ***ON COLLECTION OF GENETIC INFORMATION; APPLICATION***  
10          ***TO ALL PLANS.—Section 9802 of such Code is amended by***  
11          ***redesignating subsection (c) as subsection (f) and by insert-***  
12          ***ing after subsection (b) the following new subsections:***

13           ***“(c) GENETIC TESTING.—***

14                   ***“(1) LIMITATION ON REQUESTING OR REQUIRING***  
15                   ***GENETIC TESTING.—A group health plan may not re-***  
16                   ***quest or require an individual or a family member of***  
17                   ***such individual to undergo a genetic test.***

18                   ***“(2) RULE OF CONSTRUCTION.—Paragraph (1)***  
19                   ***shall not be construed to limit the authority of a***  
20                   ***health care professional who is providing health care***  
21                   ***services to an individual to request that such indi-***  
22                   ***vidual undergo a genetic test.***

23                   ***“(3) RULE OF CONSTRUCTION REGARDING PAY-***  
24                   ***MENT.—***

1           “(A) *IN GENERAL.*—*Nothing in paragraph*  
2           *(1) shall be construed to preclude a group health*  
3           *plan from obtaining and using the results of a*  
4           *genetic test in making a determination regard-*  
5           *ing payment (as such term is defined for the*  
6           *purposes of applying the regulations promul-*  
7           *gated by the Secretary of Health and Human*  
8           *Services under part C of title XI of the Social*  
9           *Security Act and section 264 of the Health In-*  
10           *surance Portability and Accountability Act of*  
11           *1996, as may be revised from time to time) con-*  
12           *sistent with subsection (a).*

13           “(B) *LIMITATION.*—*For purposes of sub-*  
14           *paragraph (A), a group health plan may request*  
15           *only the minimum amount of information nec-*  
16           *essary to accomplish the intended purpose.*

17           “(4) *RESEARCH EXCEPTION.*—*Notwithstanding*  
18           *paragraph (1), a group health plan may request, but*  
19           *not require, that a participant or beneficiary undergo*  
20           *a genetic test if each of the following conditions is*  
21           *met:*

22           “(A) *The request is made pursuant to re-*  
23           *search that complies with part 46 of title 45,*  
24           *Code of Federal Regulations, or equivalent Fed-*  
25           *eral regulations, and any applicable State or*

1           *local law or regulations for the protection of*  
2           *human subjects in research.*

3           “(B) *The plan clearly indicates to each par-*  
4           *ticipant or beneficiary, or in the case of a minor*  
5           *child, to the legal guardian of such beneficiary,*  
6           *to whom the request is made that—*

7                     “(i) *compliance with the request is vol-*  
8                     *untary; and*

9                     “(ii) *non-compliance will have no ef-*  
10                    *fect on enrollment status or premium or*  
11                    *contribution amounts.*

12           “(C) *No genetic information collected or ac-*  
13           *quired under this paragraph shall be used for*  
14           *underwriting purposes.*

15           “(D) *The plan notifies the Secretary in*  
16           *writing that the plan is conducting activities*  
17           *pursuant to the exception provided for under this*  
18           *paragraph, including a description of the activi-*  
19           *ties conducted.*

20           “(E) *The plan complies with such other*  
21           *conditions as the Secretary may by regulation*  
22           *require for activities conducted under this para-*  
23           *graph.*

24           “(d) *PROHIBITION ON COLLECTION OF GENETIC IN-*  
25           *FORMATION.—*

1           “(1) *IN GENERAL.*—A group health plan shall  
2           not request, require, or purchase genetic information  
3           for underwriting purposes (as defined in section  
4           9832).

5           “(2) *PROHIBITION ON COLLECTION OF GENETIC*  
6           *INFORMATION PRIOR TO ENROLLMENT.*—A group  
7           health plan shall not request, require, or purchase ge-  
8           netic information with respect to any individual  
9           prior to such individual’s enrollment under the plan  
10          or in connection with such enrollment.

11          “(3) *INCIDENTAL COLLECTION.*—If a group  
12          health plan obtains genetic information incidental to  
13          the requesting, requiring, or purchasing of other in-  
14          formation concerning any individual, such request,  
15          requirement, or purchase shall not be considered a  
16          violation of paragraph (2) if such request, require-  
17          ment, or purchase is not in violation of paragraph  
18          (1).

19          “(e) *APPLICATION TO ALL PLANS.*—The provisions of  
20          subsections (a)(1)(F), (b)(3), (c), and (d) and subsection  
21          (b)(1) and section 9801 with respect to genetic information,  
22          shall apply to group health plans without regard to section  
23          9831(a)(2).”.

1       (c) *APPLICATION TO GENETIC INFORMATION OF A*  
2 *FETUS OR EMBRYO.*—Such section is further amended by  
3 adding at the end the following:

4       “(f) *GENETIC INFORMATION OF A FETUS OR EM-*  
5 *BRYO.*—Any reference in this chapter to genetic information  
6 concerning an individual or family member of an indi-  
7 vidual shall—

8           “(1) with respect to such an individual or family  
9 member of an individual who is a pregnant woman,  
10 include genetic information of any fetus carried by  
11 such pregnant woman; and

12           “(2) with respect to an individual or family  
13 member utilizing an assisted reproductive technology,  
14 include genetic information of any embryo legally  
15 held by the individual or family member.”.

16       (d) *DEFINITIONS.*—Subsection (d) of section 9832 of  
17 such Code is amended by adding at the end the following:

18           “(6) *FAMILY MEMBER.*—The term ‘family mem-  
19 ber’ means, with respect to any individual—

20           “(A) a dependent (as such term is used for  
21 purposes of section 9801(f)(2)) of such indi-  
22 vidual, and

23           “(B) any other individual who is a first-de-  
24 gree, second-degree, third-degree, or fourth-degree

1           *relative of such individual or of an individual*  
2           *described in subparagraph (A).*

3           “(7) *GENETIC INFORMATION.*—

4                 “(A) *IN GENERAL.*—*The term ‘genetic infor-*  
5                 *mation’ means, with respect to any individual,*  
6                 *information about—*

7                         “(i) *such individual’s genetic tests,*

8                         “(ii) *the genetic tests of family mem-*  
9                         *bers of such individual, and*

10                         “(iii) *the manifestation of a disease or*  
11                         *disorder in family members of such indi-*  
12                         *vidual.*

13                 “(B) *INCLUSION OF GENETIC SERVICES AND*  
14                 *PARTICIPATION IN GENETIC RESEARCH.*—*Such*  
15                 *term includes, with respect to any individual,*  
16                 *any request for, or receipt of, genetic services, or*  
17                 *participation in clinical research which includes*  
18                 *genetic services, by such individual or any fam-*  
19                 *ily member of such individual.*

20                 “(C) *EXCLUSIONS.*—*The term ‘genetic infor-*  
21                 *mation’ shall not include information about the*  
22                 *sex or age of any individual.*

23           “(8) *GENETIC TEST.*—

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

1            *mosomes, proteins, or metabolites, that detects*  
 2            *genotypes, mutations, or chromosomal changes.*

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

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

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

15           “(9) *GENETIC SERVICES.*—*The term ‘genetic*  
 16           *services’ means—*

17           “(A) *a genetic test;*

18           “(B) *genetic counseling (including obtain-*  
 19           *ing, interpreting, or assessing genetic informa-*  
 20           *tion); or*

21           “(C) *genetic education.*

22           “(10) *UNDERWRITING PURPOSES.*—*The term*  
 23           *‘underwriting purposes’ means, with respect to any*  
 24           *group health plan, or health insurance coverage of-*  
 25           *fered in connection with a group health plan—*



1           “(A) rules for, or determination of, eligi-  
2           bility (including enrollment and continued eligi-  
3           bility) for benefits under the plan or coverage;

4           “(B) the computation of premium or con-  
5           tribution amounts under the plan or coverage;

6           “(C) the application of any pre-existing  
7           condition exclusion under the plan or coverage;  
8           and

9           “(D) other activities related to the creation,  
10          renewal, or replacement of a contract of health  
11          insurance or health benefits.”.

12          (e) **ENFORCEMENT.**—

13           (1) **IN GENERAL.**—Subchapter C of chapter 100  
14          of the Internal Revenue Code of 1986 (relating to gen-  
15          eral provisions) is amended by adding at the end the  
16          following new section:

17          **“SEC. 9834. ENFORCEMENT.**

18           “*For the imposition of tax on any failure of a group*  
19          *health plan to meet the requirements of this chapter, see*  
20          *section 4980D.*”.

21           (2) **CONFORMING AMENDMENT.**—The table of sec-  
22          tions for subchapter C of chapter 100 of such Code is  
23          amended by adding at the end the following new item:

“*Sec. 9834. Enforcement.*”.

24          (f) **REGULATIONS AND EFFECTIVE DATE.**—



1           “(F) *RULE OF CONSTRUCTION.*—*Nothing in*  
2           *subparagraph (E) or in subparagraphs (A) or*  
3           *(B) of subsection (x)(2) shall be construed to*  
4           *limit the ability of an issuer of a medicare sup-*  
5           *plemental policy from, to the extent otherwise*  
6           *permitted under this title—*

7                     “(i) *denying or conditioning the*  
8                     *issuance or effectiveness of the policy or in-*  
9                     *creasing the premium for an employer*  
10                    *based on the manifestation of a disease or*  
11                    *disorder of an individual who is covered*  
12                    *under the policy; or*

13                    “(ii) *increasing the premium for any*  
14                    *policy issued to an individual based on the*  
15                    *manifestation of a disease or disorder of an*  
16                    *individual who is covered under the policy*  
17                    *(in such case, the manifestation of a disease*  
18                    *or disorder in one individual cannot also be*  
19                    *used as genetic information about other*  
20                    *group members and to further increase the*  
21                    *premium for the employer).”.*

22           (b) *LIMITATIONS ON GENETIC TESTING AND GENETIC*  
23           *INFORMATION.*—

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

4           “(x) *LIMITATIONS ON GENETIC TESTING AND INFOR-*  
5           *MATION.*—

6           “(1) *GENETIC TESTING.*—

7           “(A) *LIMITATION ON REQUESTING OR RE-*  
8           *QUIRING GENETIC TESTING.*—An issuer of a  
9           medicare supplemental policy shall not request  
10          or require an individual or a family member of  
11          such individual to undergo a genetic test.

12          “(B) *RULE OF CONSTRUCTION.*—Subpara-  
13          graph (A) shall not be construed to limit the au-  
14          thority of a health care professional who is pro-  
15          viding health care services to an individual to  
16          request that such individual undergo a genetic  
17          test.

18          “(C) *RULE OF CONSTRUCTION REGARDING*  
19          *PAYMENT.*—

20          “(i) *IN GENERAL.*—Nothing in sub-  
21          paragraph (A) shall be construed to pre-  
22          clude an issuer of a medicare supplemental  
23          policy from obtaining and using the results  
24          of a genetic test in making a determination  
25          regarding payment (as such term is defined

1           *for the purposes of applying the regulations*  
2           *promulgated by the Secretary under part C*  
3           *of title XI and section 264 of the Health In-*  
4           *surance Portability and Accountability Act*  
5           *of 1996, as may be revised from time to*  
6           *time) consistent with subsection (s)(2)(E).*

7           “(i) *LIMITATION.—For purposes of*  
8           *clause (i), an issuer of a medicare supple-*  
9           *mental policy may request only the min-*  
10          *imum amount of information necessary to*  
11          *accomplish the intended purpose.*

12          “(D) *RESEARCH EXCEPTION.—Notwith-*  
13          *standing subparagraph (A), an issuer of a medi-*  
14          *care supplemental policy may request, but not*  
15          *require, that an individual or a family member*  
16          *of such individual undergo a genetic test if each*  
17          *of the following conditions is met:*

18               “(i) *The request is made pursuant to*  
19               *research that complies with part 46 of title*  
20               *45, Code of Federal Regulations, or equiva-*  
21               *lent Federal regulations, and any applicable*  
22               *State or local law or regulations for the*  
23               *protection of human subjects in research.*

24               “(ii) *The issuer clearly indicates to*  
25               *each individual, or in the case of a minor*

1           *child, to the legal guardian of such child, to*  
2           *whom the request is made that—*

3                     *“(I) compliance with the request*  
4                     *is voluntary; and*

5                     *“(II) non-compliance will have no*  
6                     *effect on enrollment status or premium*  
7                     *or contribution amounts.*

8                     *“(iii) No genetic information collected*  
9                     *or acquired under this subparagraph shall*  
10                    *be used for underwriting, determination of*  
11                    *eligibility to enroll or maintain enrollment*  
12                    *status, premium rating, or the creation, re-*  
13                    *newal, or replacement of a plan, contract,*  
14                    *or coverage for health insurance or health*  
15                    *benefits.*

16                    *“(iv) The issuer notifies the Secretary*  
17                    *in writing that the issuer is conducting ac-*  
18                    *tivities pursuant to the exception provided*  
19                    *for under this subparagraph, including a*  
20                    *description of the activities conducted.*

21                    *“(v) The issuer complies with such*  
22                    *other conditions as the Secretary may by*  
23                    *regulation require for activities conducted*  
24                    *under this subparagraph.*

1           “(2) *PROHIBITION ON COLLECTION OF GENETIC*  
2 *INFORMATION.*—

3           “(A) *IN GENERAL.*—*An issuer of a medicare*  
4 *supplemental policy shall not request, require, or*  
5 *purchase genetic information for underwriting*  
6 *purposes (as defined in paragraph (3)).*

7           “(B) *PROHIBITION ON COLLECTION OF GE-*  
8 *NETIC INFORMATION PRIOR TO ENROLLMENT.*—  
9 *An issuer of a medicare supplemental policy*  
10 *shall not request, require, or purchase genetic in-*  
11 *formation with respect to any individual prior*  
12 *to such individual’s enrollment under the policy*  
13 *in connection with such enrollment.*

14           “(C) *INCIDENTAL COLLECTION.*—*If an*  
15 *issuer of a medicare supplemental policy obtains*  
16 *genetic information incidental to the requesting,*  
17 *requiring, or purchasing of other information*  
18 *concerning any individual, such request, require-*  
19 *ment, or purchase shall not be considered a vio-*  
20 *lation of subparagraph (B) if such request, re-*  
21 *quirement, or purchase is not in violation of sub-*  
22 *paragraph (A).*

23           “(3) *DEFINITIONS.*—*In this subsection:*

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

1           *any other individual who is a first-degree, sec-*  
2           *ond-degree, third-degree, or fourth-degree relative*  
3           *of such individual.*

4           “(B) *GENETIC INFORMATION.*—

5                   “(i) *IN GENERAL.*—*The term ‘genetic*  
6                   *information’ means, with respect to any in-*  
7                   *dividual, information about—*

8                           “(I) *such individual’s genetic*  
9                           *tests,*

10                           “(II) *the genetic tests of family*  
11                           *members of such individual, and*

12                           “(III) *subject to clause (iv), the*  
13                           *manifestation of a disease or disorder*  
14                           *in family members of such individual.*

15                   “(ii) *INCLUSION OF GENETIC SERVICES*  
16                   *AND PARTICIPATION IN GENETIC RE-*  
17                   *SEARCH.*—*Such term includes, with respect*  
18                   *to any individual, any request for, or re-*  
19                   *ceipt of, genetic services, or participation in*  
20                   *clinical research which includes genetic*  
21                   *services, by such individual or any family*  
22                   *member of such individual.*

23                   “(iii) *EXCLUSIONS.*—*The term ‘genetic*  
24                   *information’ shall not include information*  
25                   *about the sex or age of any individual.*



1           “(C) *GENETIC TEST.*—

2                   “(i) *IN GENERAL.*—*The term ‘genetic*  
3 *test’ means an analysis of human DNA,*  
4 *RNA, chromosomes, proteins, or metabolites,*  
5 *that detects genotypes, mutations, or chro-*  
6 *mosomal changes.*

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

9                           “(I) *an analysis of proteins or*  
10 *metabolites that does not detect*  
11 *genotypes, mutations, or chromosomal*  
12 *changes; or*

13                           “(II) *an analysis of proteins or*  
14 *metabolites that is directly related to a*  
15 *manifested disease, disorder, or patho-*  
16 *logical condition that could reasonably*  
17 *be detected by a health care profes-*  
18 *sional with appropriate training and*  
19 *expertise in the field of medicine in-*  
20 *volved.*

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

23                   “(i) *a genetic test;*

1           “(ii) *genetic counseling (including ob-*  
 2           *taining, interpreting, or assessing genetic*  
 3           *information); or*

4           “(iii) *genetic education.*

5           “(E) *UNDERWRITING PURPOSES.—The term*  
 6           *‘underwriting purposes’ means, with respect to a*  
 7           *medicare supplemental policy—*

8           “(i) *rules for, or determination of, eli-*  
 9           *gibility (including enrollment and contin-*  
 10           *ued eligibility) for benefits under the policy;*

11           “(ii) *the computation of premium or*  
 12           *contribution amounts under the policy;*

13           “(iii) *the application of any pre-exist-*  
 14           *ing condition exclusion under the policy;*  
 15           *and*

16           “(iv) *other activities related to the cre-*  
 17           *ation, renewal, or replacement of a contract*  
 18           *of health insurance or health benefits.*

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

24           “(2) *APPLICATION TO GENETIC INFORMATION OF A*  
 25           *FETUS OR EMBRYO.—Section 1882(x) of such Act, as*

1       *added by paragraph (1), is further amended by add-*  
2       *ing at the end the following:*

3               “(4) *GENETIC INFORMATION OF A FETUS OR EM-*  
4       *BRYO.—Any reference in this section to genetic infor-*  
5       *mation concerning an individual or family member*  
6       *of an individual shall—*

7               “(A) *with respect to such an individual or*  
8       *family member of an individual who is a preg-*  
9       *nant woman, include genetic information of any*  
10       *fetus carried by such pregnant woman; and*

11              “(B) *with respect to an individual or fam-*  
12       *ily member utilizing an assisted reproductive*  
13       *technology, include genetic information of any*  
14       *embryo legally held by the individual or family*  
15       *member.”.*

16              “(3) *CONFORMING AMENDMENT.—Section 1882(o)*  
17       *of the Social Security Act (42 U.S.C. 1395ss(o)) is*  
18       *amended by adding at the end the following:*

19              “(4) *The issuer of the medicare supplemental*  
20       *policy complies with subsection (s)(2)(E) and sub-*  
21       *section (x).”.*

22              “(c) *EFFECTIVE DATE.—The amendments made by this*  
23       *section shall apply with respect to an issuer of a medicare*  
24       *supplemental policy for policy years beginning on or after*

1 *the date that is 1 year after the date of enactment of this*  
2 *Act.*

3 *(d) TRANSITION PROVISIONS.—*

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

13 *(2) NAIC STANDARDS.—If, not later than June*  
14 *30, 2008, the National Association of Insurance Com-*  
15 *missioners (in this subsection referred to as the*  
16 *“NAIC”) modifies its NAIC Model Regulation relat-*  
17 *ing to section 1882 of the Social Security Act (re-*  
18 *ferred to in such section as the 1991 NAIC Model*  
19 *Regulation, as subsequently modified) to conform to*  
20 *the amendments made by this section, such revised*  
21 *regulation incorporating the modifications shall be*  
22 *considered to be the applicable NAIC model regulation*  
23 *(including the revised NAIC model regulation and the*  
24 *1991 NAIC Model Regulation) for the purposes of*  
25 *such section.*

1           (3) *SECRETARY STANDARDS.*—*If the NAIC does*  
2           *not make the modifications described in paragraph*  
3           *(2) within the period specified in such paragraph, the*  
4           *Secretary of Health and Human Services shall, not*  
5           *later than October 1, 2008, make the modifications*  
6           *described in such paragraph and such revised regula-*  
7           *tion incorporating the modifications shall be consid-*  
8           *ered to be the appropriate regulation for the purposes*  
9           *of such section.*

10           (4) *DATE SPECIFIED.*—

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

14                   (i) *the date the State changes its stat-*  
15                   *utes or regulations to conform its regulatory*  
16                   *program to the changes made by this sec-*  
17                   *tion, or*

18                   (ii) *October 1, 2008.*

19           (B) *ADDITIONAL LEGISLATIVE ACTION RE-*  
20           *QUIRED.*—*In the case of a State which the Sec-*  
21           *retary identifies as—*

22                   (i) *requiring State legislation (other*  
23                   *than legislation appropriating funds) to*  
24                   *conform its regulatory program to the*  
25                   *changes made in this section, but*



1 *that issues health insurance coverage, or issuer of a*  
2 *medicare supplemental policy of protected health in-*  
3 *formation that is genetic information about an indi-*  
4 *vidual for underwriting purposes under the group*  
5 *health plan, health insurance coverage, or medicare*  
6 *supplemental policy shall not be a permitted use or*  
7 *disclosure.*

8 “(b) *DEFINITIONS.—For purposes of this section:*

9       “(1) *GENETIC INFORMATION; GENETIC TEST;*  
10 *FAMILY MEMBER.—The terms ‘genetic information’,*  
11 *‘genetic test’, and ‘family member’ have the meanings*  
12 *given such terms in section 2791 of the Public Health*  
13 *Service Act (42 U.S.C. 300gg–91), as amended by the*  
14 *Genetic Information Nondiscrimination Act of 2007.*

15       “(2) *GROUP HEALTH PLAN; HEALTH INSURANCE*  
16 *COVERAGE; MEDICARE SUPPLEMENTAL POLICY.—The*  
17 *terms ‘group health plan’ and ‘health insurance cov-*  
18 *erage’ have the meanings given such terms under sec-*  
19 *tion 2791 of the Public Health Service Act (42 U.S.C.*  
20 *300gg–91), and the term ‘medicare supplemental pol-*  
21 *icy’ has the meaning given such term in section*  
22 *1882(g).*

23       “(3) *HIPAA PRIVACY REGULATION.—The term*  
24 *‘HIPAA privacy regulation’ means the regulations*  
25 *promulgated by the Secretary under this part and*

1 *section 264 of the Health Insurance Portability and*  
2 *Accountability Act of 1996 (42 U.S.C. 1320d–2 note).*

3 “(4) *UNDERWRITING PURPOSES.*—*The term ‘un-*  
4 *derwriting purposes’ means, with respect to a group*  
5 *health plan, health insurance coverage, or a medicare*  
6 *supplemental policy—*

7 “(A) *rules for, or determination of, eligi-*  
8 *bility (including enrollment and continued eligi-*  
9 *bility) for, or determination of, benefits under*  
10 *the plan, coverage, or policy;*

11 “(B) *the computation of premium or con-*  
12 *tribution amounts under the plan, coverage, or*  
13 *policy;*

14 “(C) *the application of any pre-existing*  
15 *condition exclusion under the plan, coverage, or*  
16 *policy; and*

17 “(D) *other activities related to the creation,*  
18 *renewal, or replacement of a contract of health*  
19 *insurance or health benefits.*

20 “(c) *PROCEDURE.*—*The revisions under subsection (a)*  
21 *shall be made by notice in the Federal Register published*  
22 *not later than 60 days after the date of the enactment of*  
23 *this section and shall be effective upon publication, without*  
24 *opportunity for any prior public comment, but may be re-*



1 *vised, consistent with this section, after opportunity for*  
2 *public comment.*

3       “(d) *ENFORCEMENT.*—*In addition to any other sanc-*  
4 *tions or remedies that may be available under law, a cov-*  
5 *ered entity that is a group health plan, health insurance*  
6 *issuer, or issuer of a medicare supplemental policy and that*  
7 *violates the HIPAA privacy regulation (as revised under*  
8 *subsection (a) or otherwise) with respect to the use or disclo-*  
9 *sure of genetic information shall be subject to the penalties*  
10 *described in sections 1176 and 1177 in the same manner*  
11 *and to the same extent that such penalties apply to viola-*  
12 *tions of this part.”.*

13       (b) *REGULATIONS; EFFECTIVE DATE.*—

14           (1) *REGULATIONS.*—*Not later than 12 months*  
15 *after the date of the enactment of this Act, the Sec-*  
16 *retary of Health and Human Services shall issue*  
17 *final regulations to carry out the revision required by*  
18 *section 1180(a) of the Social Security Act, as added*  
19 *by subsection (a). The Secretary has the sole authority*  
20 *to promulgate such regulations, but shall promulgate*  
21 *such regulations in consultation with the Secretaries*  
22 *of Labor and the Treasury.*

23           (2) *EFFECTIVE DATE.*—*The amendment made by*  
24 *subsection (a) shall take effect on the date that is 1*  
25 *year after the date of the enactment of this Act.*

1 **SEC. 106. ASSURING COORDINATION.**

2 *Except as provided in section 105(b)(1), the Secretary*  
3 *of Health and Human Services, the Secretary of Labor, and*  
4 *the Secretary of the Treasury shall ensure, through the exe-*  
5 *cution of an interagency memorandum of understanding*  
6 *among such Secretaries, that—*

7 (1) *regulations, rulings, and interpretations*  
8 *issued by such Secretaries relating to the same matter*  
9 *over which two or more such Secretaries have respon-*  
10 *sibility under this title (and the amendments made by*  
11 *this title) are administered so as to have the same ef-*  
12 *fect at all times; and*

13 (2) *coordination of policies relating to enforcing*  
14 *the same requirements through such Secretaries in*  
15 *order to have a coordinated enforcement strategy that*  
16 *avoids duplication of enforcement efforts and assigns*  
17 *priorities in enforcement.*

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

22 **SEC. 201. DEFINITIONS.**

23 *In this title:*

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

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

3                (2) *EMPLOYEE; EMPLOYER; EMPLOYMENT AGEN-*  
4        *CY; LABOR ORGANIZATION; MEMBER.—*

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

3           (A) *a dependent (as such term is used for*  
4 *purposes of section 701(f)(2) of the Employee Re-*  
5 *tirement Income Security Act of 1974) of such*  
6 *individual, and*

7           (B) *any other individual who is a first-de-*  
8 *gree, second-degree, third-degree, or fourth-degree*  
9 *relative of such individual or of an individual*  
10 *described in subparagraph (A).*

11       (4) *GENETIC INFORMATION.*—

12           (A) *IN GENERAL.*—*The term “genetic infor-*  
13 *mation” means, with respect to any individual,*  
14 *information about—*

15           (i) *such individual’s genetic tests,*

16           (ii) *the genetic tests of family members*  
17 *of such individual, and*

18           (iii) *the manifestation of a disease or*  
19 *disorder in family members of such indi-*  
20 *vidual.*

21           (B) *INCLUSION OF GENETIC SERVICES AND*  
22 *PARTICIPATION IN GENETIC RESEARCH.*—*Such*  
23 *term includes, with respect to any individual,*  
24 *any request for, or receipt of, genetic services, or*  
25 *participation in clinical research which includes*

1           *genetic services, by such individual or any fam-*  
2           *ily member of such individual.*

3           (C) *EXCLUSIONS.*—*The term “genetic infor-*  
4           *mation” shall not include information about the*  
5           *sex or age of any individual.*

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

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

18                 (A) *a genetic test;*

19                 (B) *genetic counseling (including obtaining,*  
20                 *interpreting, or assessing genetic information);*  
21                 *or*

22                 (C) *genetic education.*

23          (7) *GENETIC TEST.*—

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

1            *mosomes, proteins, or metabolites, that detects*  
2            *genotypes, mutations, or chromosomal changes.*

3            (B) *EXCEPTIONS.—The term “genetic test”*  
4            *does not mean an analysis of proteins or metabo-*  
5            *lites that does not detect genotypes, mutations, or*  
6            *chromosomal changes.*

7 **SEC. 202. EMPLOYER PRACTICES.**

8            (a) *DISCRIMINATION BASED ON GENETIC INFORMA-*  
9            *TION.—It shall be an unlawful employment practice for an*  
10           *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 to*  
16           *the employee; or*

17           (2) *to limit, segregate, or classify the employees*  
18           *of the employer in any way that would deprive or*  
19           *tend to deprive any employee of employment opportu-*  
20           *nities or otherwise adversely affect the status of the*  
21           *employee as an employee, because of genetic informa-*  
22           *tion with respect to the employee.*

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

1 *to an employee or a family member of the employee*  
2 *except—*

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

6           (2) *where—*

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

10              (B) *the employee provides prior, knowing,*  
11 *voluntary, and written authorization;*

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

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



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

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

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

15                (A) the employer provides written notice of  
16                the genetic monitoring to the employee;

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

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

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

23                (D) the monitoring is in compliance with—

24                       (i) any Federal genetic monitoring reg-  
25                       ulations, including any such regulations

1           *that may be promulgated by the Secretary*  
2           *of Labor pursuant to the Occupational*  
3           *Safety and Health Act of 1970 (29 U.S.C.*  
4           *651 et seq.), the Federal Mine Safety and*  
5           *Health Act of 1977 (30 U.S.C. 801 et seq.),*  
6           *or the Atomic Energy Act of 1954 (42*  
7           *U.S.C. 2011 et seq.); or*

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

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

20                    *(6) where the employer conducts DNA analysis*  
21            *for law enforcement purposes as a forensic laboratory,*  
22            *and such analysis is included in the Combined DNA*  
23            *Index System pursuant to section 210304 of the Vio-*  
24            *lent Crime Control and Law Enforcement Act of 1994*  
25            *(42 U.S.C. 14132), and requests or requires genetic*

1        *information of such employer's employees, but only to*  
2        *the extent that such genetic information is used for*  
3        *analysis of DNA identification markers for quality*  
4        *control to detect sample contamination.*

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

10    **SEC. 203. EMPLOYMENT AGENCY PRACTICES.**

11        *(a) DISCRIMINATION BASED ON GENETIC INFORMA-*  
12        *TION.—It shall be an unlawful employment practice for an*  
13        *employment agency—*

14                *(1) to fail or refuse to refer for employment, or*  
15        *otherwise to discriminate against, any individual be-*  
16        *cause of genetic information with respect to the indi-*  
17        *vidual;*

18                *(2) to limit, segregate, or classify individuals or*  
19        *fail or refuse to refer for employment any individual*  
20        *in any way that would deprive or tend to deprive any*  
21        *individual of employment opportunities, or otherwise*  
22        *adversely affect the status of the individual as an em-*  
23        *ployee, because of genetic information with respect to*  
24        *the individual; or*

1           (3) *to cause or attempt to cause an employer to*  
2           *discriminate against an individual in violation of*  
3           *this title.*

4           (b) *ACQUISITION OF GENETIC INFORMATION.—It shall*  
5           *be an unlawful employment practice for an employment*  
6           *agency to request, require, or purchase genetic information*  
7           *with respect to an individual or a family member of the*  
8           *individual except—*

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

12                   (2) *where—*

13                           (A) *health or genetic services are offered by*  
14            *the employment agency, including such services*  
15            *offered as part of a wellness program;*

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

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

1           (D) any individually identifiable genetic  
2           information provided under subparagraph (C) in  
3           connection with the services provided under sub-  
4           paragraph (A) is only available for purposes of  
5           such services and shall not be disclosed to the em-  
6           ployment agency except in aggregate terms that  
7           do not disclose the identity of specific individ-  
8           uals;

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

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

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

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

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

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

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

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

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

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

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

1            *netic monitoring program, receives the results of*  
2            *the monitoring only in aggregate terms that do*  
3            *not disclose the identity of specific individuals.*

4            *(c) PRESERVATION OF PROTECTIONS.—In the case of*  
5            *information to which any of paragraphs (1) through (5)*  
6            *of subsection (b) applies, such information may not be used*  
7            *in violation of paragraph (1), (2), or (3) of subsection (a)*  
8            *or treated or disclosed in a manner that violates section*  
9            *206.*

10    **SEC. 204. LABOR ORGANIZATION PRACTICES.**

11            *(a) DISCRIMINATION BASED ON GENETIC INFORMA-*  
12            *TION.—It shall be an unlawful employment practice for a*  
13            *labor organization—*

14            *(1) to exclude or to expel from the membership*  
15            *of the organization, or otherwise to discriminate*  
16            *against, any member because of genetic information*  
17            *with respect to the member;*

18            *(2) to limit, segregate, or classify the members of*  
19            *the organization, or fail or refuse to refer for employ-*  
20            *ment any member, in any way that would deprive or*  
21            *tend to deprive any member of employment opportu-*  
22            *nities, or otherwise adversely affect the status of the*  
23            *member as an employee, because of genetic informa-*  
24            *tion with respect to the member; or*

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

4           (b) *ACQUISITION OF GENETIC INFORMATION.—It shall*  
5           *be an unlawful employment practice for a labor organiza-*  
6           *tion to request, require, or purchase genetic information*  
7           *with respect to a member or a family member of the member*  
8           *except—*

9                   (1) *where a labor organization inadvertently re-*  
10                  *quests or requires family medical history of the mem-*  
11                  *ber or family member of the member;*

12                  (2) *where—*

13                           (A) *health or genetic services are offered by*  
14                           *the labor organization, including such services*  
15                           *offered as part of a wellness program;*

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

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



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

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

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

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

22                 (A) the labor organization provides written  
23                 notice of the genetic monitoring to the member;

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

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

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

5           (D) the monitoring is in compliance with—

6                 (i) any Federal genetic monitoring reg-  
7                 ulations, 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 seq.),  
13                or the Atomic Energy Act of 1954 (42  
14                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 labor organization, excluding any  
22           licensed health care professional or board cer-  
23           tified genetic counselor that is involved in the ge-  
24           netic monitoring program, receives the results of

1           *the monitoring only in aggregate terms that do*  
2           *not disclose the identity of specific members.*

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

9   **SEC. 205. TRAINING PROGRAMS.**

10          *(a) DISCRIMINATION BASED ON GENETIC INFORMA-*  
11 *TION.—It shall be an unlawful employment practice for any*  
12 *employer, labor organization, or joint labor-management*  
13 *committee controlling apprenticeship or other training or*  
14 *retraining, including on-the-job training programs—*

15            *(1) to discriminate against any individual be-*  
16            *cause of genetic information with respect to the indi-*  
17            *vidual in admission to, or employment in, any pro-*  
18            *gram established to provide apprenticeship or other*  
19            *training or retraining;*

20            *(2) to limit, segregate, or classify the applicants*  
21            *for or participants in such apprenticeship or other*  
22            *training or retraining, or fail or refuse to refer for*  
23            *employment any individual, in any way that would*  
24            *deprive or tend to deprive any individual of employ-*  
25            *ment opportunities, or otherwise adversely affect the*

1       *status of the individual as an employee, because of ge-*  
2       *netic information with respect to the individual; or*

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

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

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

17             (2) *where—*

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

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

24                 (C) *only the individual (or family member*  
25       *if the family member is receiving genetic serv-*

1            *ices) and the licensed health care professional or*  
2            *board certified genetic counselor involved in pro-*  
3            *viding such services receive individually identifi-*  
4            *able information concerning the results of such*  
5            *services; and*

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

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

22           *(4) where the employer, labor organization, or*  
23           *joint labor-management committee purchases docu-*  
24           *ments that are commercially and publicly available*  
25           *(including newspapers, magazines, periodicals, and*

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

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

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

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

12              *(ii) the genetic monitoring is required by*  
13       *Federal or State law;*

14              *(C) the individual is informed of individual*  
15       *monitoring results;*

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

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

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

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

15                  (6) *where the employer conducts DNA analysis*  
16                  *for law enforcement purposes as a forensic laboratory,*  
17                  *and such analysis is included in the Combined DNA*  
18                  *Index System pursuant to section 210304 of the Vio-*  
19                  *lent Crime Control and Law Enforcement Act of 1994*  
20                  *(42 U.S.C. 14132), and requests or requires genetic*  
21                  *information of such employer's apprentices or train-*  
22                  *ees, but only to the extent that such genetic informa-*  
23                  *tion is used for analysis of DNA identification mark-*  
24                  *ers for quality control to detect sample contamina-*  
25                  *tion.*

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

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

8       (a) *TREATMENT OF INFORMATION AS PART OF CON-*  
9 *FIDENTIAL MEDICAL RECORD.*—*If an employer, employ-*  
10 *ment agency, labor organization, or joint labor-manage-*  
11 *ment committee possesses genetic information about an em-*  
12 *ployee or member, such information shall be maintained on*  
13 *separate forms and in separate medical files and be treated*  
14 *as a confidential medical record of the employee or member.*  
15 *An employer, employment agency, labor organization, or*  
16 *joint labor-management committee shall be considered to be*  
17 *in compliance with the maintenance of information re-*  
18 *quirements of this subsection with respect to genetic infor-*  
19 *mation subject to this subsection that is maintained with*  
20 *and treated as a confidential medical record under section*  
21 *102(d)(3)(B) of the Americans With Disabilities Act (42*  
22 *U.S.C. 12112(d)(3)(B)).*

23       (b) *LIMITATION ON DISCLOSURE.*—*An employer, em-*  
24 *ployment agency, labor organization, or joint labor-man-*



1 *agement committee shall not disclose genetic information*  
2 *concerning an employee or member except—*

3 *(1) to the employee or member of a labor organi-*  
4 *zation (or family member if the family member is re-*  
5 *ceiving the genetic services) at the written request of*  
6 *the employee or member of such organization;*

7 *(2) to an occupational or other health researcher*  
8 *if the research is conducted in compliance with the*  
9 *regulations and protections provided for under part*  
10 *46 of title 45, Code of Federal Regulations;*

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

13 *(A) the employer, employment agency, labor*  
14 *organization, or joint labor-management com-*  
15 *mittee may disclose only the genetic information*  
16 *expressly authorized by such order; and*

17 *(B) if the court order was secured without*  
18 *the knowledge of the employee or member to*  
19 *whom the information refers, the employer, em-*  
20 *ployment agency, labor organization, or joint*  
21 *labor-management committee shall inform the*  
22 *employee or member of the court order and any*  
23 *genetic information that was disclosed pursuant*  
24 *to such order;*

1           (4) to government officials who are investigating  
2           compliance with this title if the information is rel-  
3           evant to the investigation;

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

10          (6) to a Federal, State, or local public health  
11          agency only with regard to information that is de-  
12          scribed in section 201(4)(A)(iii) and that concerns a  
13          contagious disease that presents an imminent hazard  
14          of death or life-threatening illness, and that the em-  
15          ployee whose family member or family members is or  
16          are the subject of a disclosure under this paragraph  
17          is notified of such disclosure.

18          (c) *RELATIONSHIP TO HIPAA REGULATIONS.*—With  
19          respect to the regulations promulgated by the Secretary of  
20          Health and Human Services under part C of title XI of  
21          the Social Security Act (42 U.S.C. 1320d et seq.) and sec-  
22          tion 264 of the Health Insurance Portability and Account-  
23          ability Act of 1996 (42 U.S.C. 1320d–2 note), this title does  
24          not prohibit a covered entity under such regulations from  
25          any use or disclosure of health information that is author-

1 ized for the covered entity under such regulations. The pre-  
2 vious sentence does not affect the authority of such Secretary  
3 to modify such regulations.

4 **SEC. 207. REMEDIES AND ENFORCEMENT.**

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

7 (1) *IN GENERAL.*—*The powers, procedures, and*  
8 *remedies provided in sections 705, 706, 707, 709, 710,*  
9 *and 711 of the Civil Rights Act of 1964 (42 U.S.C.*  
10 *2000e–4 et seq.) to the Commission, the Attorney Gen-*  
11 *eral, or any person, alleging a violation of title VII*  
12 *of that Act (42 U.S.C. 2000e et seq.) shall be the pow-*  
13 *ers, procedures, and remedies this title provides to the*  
14 *Commission, the Attorney General, or any person, re-*  
15 *spectively, alleging an unlawful employment practice*  
16 *in violation of this title against an employee de-*  
17 *scribed in section 201(2)(A)(i), except as provided in*  
18 *paragraphs (2) and (3).*

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

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

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

13           (1) *IN GENERAL.*—*The powers, remedies, and*  
14           *procedures provided in sections 302 and 304 of the*  
15           *Government Employee Rights Act of 1991 (42 U.S.C.*  
16           *2000e–16b, 2000e–16c) to the Commission, or any*  
17           *person, alleging a violation of section 302(a)(1) of*  
18           *that Act (42 U.S.C. 2000e–16b(a)(1)) shall be the*  
19           *powers, remedies, and procedures this title provides to*  
20           *the Commission, or any person, respectively, alleging*  
21           *an unlawful employment practice in violation of this*  
22           *title against an employee described in section*  
23           *201(2)(A)(ii), except as provided in paragraphs (2)*  
24           *and (3).*

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

7           (3) *DAMAGES.*—*The powers, remedies, and pro-*  
8           *cedures provided in section 1977A of the Revised*  
9           *Statutes of the United States (42 U.S.C. 1981a), in-*  
10          *cluding the limitations contained in subsection (b)(3)*  
11          *of such section 1977A, shall be powers, remedies, and*  
12          *procedures this title provides to the Commission, or*  
13          *any person, alleging such a practice (not an employ-*  
14          *ment practice specifically excluded from coverage*  
15          *under section 1977A(a)(1) of the Revised Statutes of*  
16          *the United States).*

17          (c) *EMPLOYEES COVERED BY CONGRESSIONAL AC-*  
18          *COUNTABILITY ACT OF 1995.*—

19               (1) *IN GENERAL.*—*The powers, remedies, and*  
20               *procedures provided in the Congressional Account-*  
21               *ability Act of 1995 (2 U.S.C. 1301 et seq.) to the*  
22               *Board (as defined in section 101 of that Act (2 U.S.C.*  
23               *1301)), or any person, alleging a violation of section*  
24               *201(a)(1) of that Act (42 U.S.C. 1311(a)(1)) shall be*  
25               *the powers, remedies, and procedures this title pro-*

1 *vides to that Board, or any person, alleging an un-*  
2 *lawful employment practice in violation of this title*  
3 *against an employee described in section*  
4 *201(2)(A)(iii), 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) of*  
8 *section 722 of the Revised Statutes of the United*  
9 *States (42 U.S.C. 1988), shall be powers, remedies,*  
10 *and procedures this title provides to that Board, or*  
11 *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 of the United States (42 U.S.C. 1981a), in-*  
15 *cluding the limitations contained in subsection (b)(3)*  
16 *of such section 1977A, shall be powers, remedies, and*  
17 *procedures this title provides to that Board, or any*  
18 *person, alleging such a practice (not an employment*  
19 *practice specifically excluded from coverage under sec-*  
20 *tion 1977A(a)(1) of the Revised Statutes of the United*  
21 *States).*

22 (4) *OTHER APPLICABLE PROVISIONS.—With re-*  
23 *spect to a claim alleging a practice described in para-*  
24 *graph (1), title III of the Congressional Account-*  
25 *ability Act of 1995 (2 U.S.C. 1381 et seq.) shall apply*

1       *in the same manner as such title applies with respect*  
2       *to a claim alleging a violation of section 201(a)(1) of*  
3       *such Act (2 U.S.C. 1311(a)(1)).*

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

6               *(1) IN GENERAL.—The powers, remedies, and*  
7       *procedures provided in chapter 5 of title 3, United*  
8       *States Code, to the President, the Commission, the*  
9       *Merit Systems Protection Board, or any person, alleg-*  
10       *ing a violation of section 411(a)(1) of that title, shall*  
11       *be the powers, remedies, and procedures this title pro-*  
12       *vides to the President, the Commission, such Board,*  
13       *or any person, respectively, alleging an unlawful em-*  
14       *ployment practice in violation of this title against an*  
15       *employee described in section 201(2)(A)(iv), except as*  
16       *provided in paragraphs (2) and (3).*

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

24               *(3) DAMAGES.—The powers, remedies, and pro-*  
25       *cedures provided in section 1977A of the Revised*

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

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

11 *(1) IN GENERAL.—The powers, remedies, and*  
12 *procedures provided in section 717 of the Civil Rights*  
13 *Act of 1964 (42 U.S.C. 2000e–16) to the Commission,*  
14 *the Attorney General, the Librarian of Congress, or*  
15 *any person, alleging a violation of that section shall*  
16 *be the powers, remedies, and procedures this title pro-*  
17 *vides to the Commission, the Attorney General, the*  
18 *Librarian of Congress, or any person, respectively, al-*  
19 *leging an unlawful employment practice in violation*  
20 *of this title against an employee or applicant de-*  
21 *scribed in section 201(2)(A)(v), except as provided in*  
22 *paragraphs (2) and (3).*

23 *(2) COSTS AND FEES.—The powers, remedies,*  
24 *and procedures provided in subsections (b) and (c) of*  
25 *section 722 of the Revised Statutes of the United*



1     *States (42 U.S.C. 1988), shall be powers, remedies,*  
2     *and procedures this title provides to the Commission,*  
3     *the Attorney General, the Librarian of Congress, or*  
4     *any person, alleging such a practice.*

5             (3) *DAMAGES.—The powers, remedies, and pro-*  
6     *cedures provided in section 1977A of the Revised*  
7     *Statutes of the United States (42 U.S.C. 1981a), in-*  
8     *cluding the limitations contained in subsection (b)(3)*  
9     *of such section 1977A, shall be powers, remedies, and*  
10    *procedures this title provides to the Commission, the*  
11    *Attorney General, the Librarian of Congress, or any*  
12    *person, alleging such a practice (not an employment*  
13    *practice specifically excluded from coverage under sec-*  
14    *tion 1977A(a)(1) of the Revised Statutes of the United*  
15    *States).*

16             (f) *PROHIBITION AGAINST RETALIATION.—No person*  
17    *shall discriminate against any individual because such in-*  
18    *dividual has opposed any act or practice made unlawful*  
19    *by this title or because such individual made a charge, testi-*  
20    *fied, assisted, or participated in any manner in an inves-*  
21    *tigation, proceeding, or hearing under this title. The rem-*  
22    *edies and procedures otherwise provided for under this sec-*  
23    *tion shall be available to aggrieved individuals with respect*  
24    *to violations of this subsection.*

1       (g) *DEFINITION.*—*In this section, the term “Commis-*  
2 *sion” means the Equal Employment Opportunity Commis-*  
3 *sion.*

4 **SEC. 208. DISPARATE IMPACT.**

5       (a) *GENERAL RULE.*—*Notwithstanding any other pro-*  
6 *vision of this Act, “disparate impact”, as that term is used*  
7 *in section 703(k) of the Civil Rights Act of 1964 (42 U.S.C.*  
8 *2000e–2(k)), on the basis of genetic information does not*  
9 *establish a cause of action under this Act.*

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

18       (c) *MEMBERSHIP.*—

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

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

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

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

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

8           (E) 1 member shall be appointed by the  
9           Speaker of the House of Representatives;

10          (F) 1 member shall be appointed by the Mi-  
11          nority Leader of the House of Representatives;

12          (G) 1 member shall be appointed by the  
13          Chairman of the Committee on Education and  
14          Labor of the House of Representatives; and

15          (H) 1 member shall be appointed by the  
16          ranking minority member of the Committee on  
17          Education and Labor of the House of Represent-  
18          atives.

19          (2) COMPENSATION AND EXPENSES.—The mem-  
20          bers of the Commission shall not receive compensation  
21          for the performance of services for the Commission,  
22          but shall be allowed travel expenses, including per  
23          diem in lieu of subsistence, at rates authorized for  
24          employees of agencies under subchapter I of chapter  
25          57 of title 5, United States Code, while away from

1     *their homes or regular places of business in the per-*  
2     *formance of services for the Commission.*

3     *(d) ADMINISTRATIVE PROVISIONS.—*

4             *(1) LOCATION.—The Commission shall be located*  
5     *in a facility maintained by the Equal Employment*  
6     *Opportunity Commission.*

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

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

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

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

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

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

15          **SEC. 209. CONSTRUCTION.**

16          (a) *IN GENERAL.*—*Nothing in this title shall be con-*  
17          *strued to—*

18                 (1) *limit the rights or protections of an indi-*  
19                 *vidual under any other Federal or State statute that*  
20                 *provides equal or greater protection to an individual*  
21                 *than the rights or protections provided for under this*  
22                 *title, including the protections of an individual under*  
23                 *the Americans with Disabilities Act of 1990 (42*  
24                 *U.S.C. 12101 et seq.) (including coverage afforded to*  
25                 *individuals under section 102 of such Act (42 U.S.C.*

1     12112)), or under the Rehabilitation Act of 1973 (29  
2     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) provide for enforcement of, or penalties for  
9     violation of, any requirement or prohibition applica-  
10    ble to any employer, employment agency, labor orga-  
11    nization, or joint labor-management committee sub-  
12    ject to enforcement for a violation under—

13            (i) the amendments made by title I of this  
14    Act;

15            (ii)(I) subsection (a) of section 701 of the  
16    Employee Retirement Income Security Act of  
17    1974 as such section applies with respect to ge-  
18    netic information pursuant to subsection  
19    (b)(1)(B) of such section;

20            (II) section 702(a)(1)(F) of such Act; or

21            (III) section 702(b)(1) of such Act as such  
22    section applies with respect to genetic informa-  
23    tion as a health status-related factor;

24            (iii)(I) subsection (a) of section 2701 of the  
25    Public Health Service Act as such section applies

- 1           *with respect to genetic information pursuant to*  
2           *subsection (b)(1)(B) of such section;*
- 3                     *(II) section 2702(a)(1)(F) of such Act; or*  
4                     *(III) section 2702(b)(1) of such Act as such*  
5           *section applies with respect to genetic informa-*  
6           *tion as a health status-related factor; or*
- 7                     *(iv)(I) subsection (a) of section 9801 of the*  
8           *Internal Revenue Code of 1986 as such section*  
9           *applies with respect to genetic information pur-*  
10          *suant to subsection (b)(1)(B) of such section;*
- 11                    *(II) section 9802(a)(1)(F) of such Act; or*  
12                    *(III) section 9802(b)(1) of such Act as such*  
13          *section applies with respect to genetic informa-*  
14          *tion as a health status-related factor;*
- 15                    *(3) apply to the Armed Forces Repository of*  
16          *Specimen Samples for the Identification of Remains;*
- 17                    *(4) limit or expand the protections, rights, or ob-*  
18          *ligations of employees or employers under applicable*  
19          *workers' compensation laws;*
- 20                    *(5) limit the authority of a Federal department*  
21          *or agency to conduct or sponsor occupational or other*  
22          *health research that is conducted in compliance with*  
23          *the regulations contained in part 46 of title 45, Code*  
24          *of Federal Regulations (or any corresponding or simi-*  
25          *lar regulation or rule);*

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

6           (7) *require any specific benefit for an employee*  
7           *or member or a family member of an employee or*  
8           *member under any group health plan or health insur-*  
9           *ance issuer offering group health insurance coverage*  
10          *in connection with a group health plan.*

11          (b) *GENETIC INFORMATION OF A FETUS OR EM-*  
12          *BRYO.—Any reference in this title to genetic information*  
13          *concerning an individual or family member of an indi-*  
14          *vidual shall—*

15                 (1) *with respect to such an individual or family*  
16                 *member of an individual who is a pregnant woman,*  
17                 *include genetic information of any fetus carried by*  
18                 *such pregnant woman; and*

19                 (2) *with respect to an individual or family mem-*  
20                 *ber utilizing an assisted reproductive technology, in-*  
21                 *clude genetic information of any embryo legally held*  
22                 *by the individual or family member.*

23          (c) *RELATION TO AUTHORITIES UNDER TITLE I.—*  
24          *With respect to a group health plan, or a health insurance*  
25          *issuer offering group health insurance coverage in connec-*



1 *tion with a group health plan, this title does not prohibit*  
2 *any activity of such plan or issuer that is authorized for*  
3 *the plan or issuer under any provision of law referred to*  
4 *in clauses (i) through (iv) of subsection (a)(2)(B).*

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

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

15 **SEC. 211. REGULATIONS.**

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

19 **SEC. 212. AUTHORIZATION OF APPROPRIATIONS.**

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

23 **SEC. 213. EFFECTIVE DATE.**

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

1       **TITLE III—MISCELLANEOUS**  
2                               **PROVISIONS**

3   **SEC. 301. SEVERABILITY.**

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

10 **SEC. 302. CHILD LABOR PROTECTIONS.**

11       *(a) IN GENERAL.—Section 16(e) of the Fair Labor*  
12 *Standards Act of 1938 (29 U.S.C. 216(e)) is amended to*  
13 *read as follows:*

14       *“(e)(1)(A) Any person who violates the provisions of*  
15 *sections 12 or 13(c), relating to child labor, or any regula-*  
16 *tion issued pursuant to such sections, shall be subject to a*  
17 *civil penalty not to exceed—*

18                       *“(i) \$11,000 for each employee who*  
19                       *was the subject of such a violation; or*

20                       *“(ii) \$50,000 with regard to each such*  
21                       *violation that causes the death or serious*  
22                       *injury of any employee under the age of 18*  
23                       *years, which penalty may be doubled where*  
24                       *the violation is a repeated or willful viola-*  
25                       *tion.*

1       “(B) For purposes of subparagraph (A), the term ‘seri-  
2   ous injury’ means—

3               “(i) permanent loss or substantial impairment of  
4   one of the senses (sight, hearing, taste, smell, tactile  
5   sensation);

6               “(ii) permanent loss or substantial impairment  
7   of the function of a bodily member, organ, or mental  
8   faculty, including the loss of all or part of an arm,  
9   leg, foot, hand or other body part; or

10              “(iii) permanent paralysis or substantial im-  
11   pairment that causes loss of movement or mobility of  
12   an arm, leg, foot, hand or other body part.

13       “(2) Any person who repeatedly or willfully violates  
14   section 6 or 7, relating to wages, shall be subject to a civil  
15   penalty not to exceed \$1,100 for each such violation.

16       “(3) In determining the amount of any penalty under  
17   this subsection, the appropriateness of such penalty to the  
18   size of the business of the person charged and the gravity  
19   of the violation shall be considered. The amount of any pen-  
20   alty under this subsection, when finally determined, may  
21   be—

22              “(A) deducted from any sums owing by the  
23   United States to the person charged;

24              “(B) recovered in a civil action brought by the  
25   Secretary in any court of competent jurisdiction, in

1       *which litigation the Secretary shall be represented by*  
2       *the Solicitor of Labor; or*

3               “(C) *ordered by the court, in an action brought*  
4       *for a violation of section 15(a)(4) or a repeated or*  
5       *willful violation of section 15(a)(2), to be paid to the*  
6       *Secretary.*

7               “(4) *Any administrative determination by the Sec-*  
8       *retary of the amount of any penalty under this subsection*  
9       *shall be final, unless within 15 days after receipt of notice*  
10       *thereof by certified mail the person charged with the viola-*  
11       *tion takes exception to the determination that the violations*  
12       *for which the penalty is imposed occurred, in which event*  
13       *final determination of the penalty shall be made in an ad-*  
14       *ministrative proceeding after opportunity for hearing in*  
15       *accordance with section 554 of title 5, United States Code,*  
16       *and regulations to be promulgated by the Secretary.*

17               “(5) *Except for civil penalties collected for violations*  
18       *of section 12, sums collected as penalties pursuant to this*  
19       *section shall be applied toward reimbursement of the costs*  
20       *of determining the violations and assessing and collecting*  
21       *such penalties, in accordance with the provision of section*  
22       *2 of the Act entitled ‘An Act to authorize the Department*  
23       *of Labor to make special statistical studies upon payment*  
24       *of the cost thereof and for other purposes’ (29 U.S.C. 9a).*

1 *Civil penalties collected for violations of section 12 shall*  
2 *be deposited in the general fund of the Treasury.”.*

3       **(b) EFFECTIVE DATE.**—*The amendments made by this*  
4 *section shall take effect on the date of the enactment of this*  
5 *Act.*

Attest:

*Secretary.*

110<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

**H.R. 493**

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**AMENDMENT**