

108TH CONGRESS
1ST SESSION

H. R. 1910

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

IN THE HOUSE OF REPRESENTATIVES

MAY 1, 2003

Ms. SLAUGHTER (for herself, Mr. ABERCROMBIE, Mr. ACKERMAN, Mr. ALLEN, Ms. BERKLEY, Mr. BERMAN, Mrs. BIGGERT, Mr. BISHOP of New York, Ms. BORDALLO, Mr. BOSWELL, Mr. BOYD, Mr. BURTON of Indiana, Mrs. CAPPS, Mr. CAPUANO, Mr. CARDIN, Ms. CARSON of Indiana, Mr. CASE, Mrs. CHRISTENSEN, Mr. COOPER, Mr. COSTELLO, Mr. CROWLEY, Mr. CUMMINGS, Mr. DAVIS of Florida, Mrs. DAVIS of California, Mr. DEFAZIO, Ms. DEGETTE, Ms. DELAURO, Mr. DICKS, Mr. DINGELL, Mr. DOYLE, Mr. ENGEL, Mr. FARR, Mr. FOLEY, Mr. FRANK of Massachusetts, Mr. FRELINGHUYSEN, Mr. FROST, Mr. GILCHREST, Mr. GILLMOR, Mr. GORDON, Ms. GRANGER, Mr. GREEN of Texas, Mr. GUTIERREZ, Mr. HEFLEY, Mr. HINCHEY, Mr. HINOJOSA, Mr. HOEFFEL, Mr. HOLT, Mr. HYDE, Mr. INSLEE, Mr. ISRAEL, Ms. JACKSON-LEE of Texas, Ms. EDDIE BERNICE JOHNSON of Texas, Mrs. JONES of Ohio, Mr. KANJORSKI, Ms. KAPTUR, Mrs. KELLY, Mr. KENNEDY of Rhode Island, Mr. KILDEE, Mr. KING of New York, Mr. KUCINICH, Mr. LANTOS, Mr. LATOURETTE, Mr. LEACH, Mr. LOBIONDO, Ms. LOFGREN, Mrs. LOWEY, Mrs. MALONEY, Mr. MARKEY, Mr. MATSUI, Mrs. MCCARTHY of New York, Mr. MCDERMOTT, Mr. MCHUGH, Mr. MCINTYRE, Mr. McNULTY, Mr. MEEHAN, Mr. MENENDEZ, Mr. MICA, Ms. MILLENDER-MCDONALD, Mr. GEORGE MILLER of California, Mr. MOORE, Mr. MORAN of Virginia, Mr. NADLER, Mr. NEY, Mrs. NORTHUP, Ms. NORTON, Mr. OBEY, Mr. OWENS, Ms. PELOSI, Mr. PLATTS, Mr. RANGEL, Mr. ROTHMAN, Ms. ROYBAL-ALLARD, Ms. LINDA T. SÁNCHEZ of California, Ms. LORETTA SANCHEZ of California, Mr. SANDERS, Ms. SCHAKOWSKY, Mr. SCHIFF, Mr. SERRANO, Mr. SHAYS, Mr. SHERMAN, Mr. SIMMONS, Mr. STARK, Mr. STRICKLAND, Mrs. TAUSCHER, Mr. TIERNEY, Mr. UDALL of New Mexico, Ms. VELÁZQUEZ, Mr. WALSH, Mr. WAMP, Mr. WAXMAN, Mr. WEXLER, and Ms. WOOLSEY) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committees on Ways and Means and Education and the Workforce, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

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

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

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

4 (a) SHORT TITLE.—This title may be cited as the
5 “Genetic Nondiscrimination in Health Insurance and Em-
6 ployment Act”.

7 (b) TABLE OF CONTENTS.—The table of contents is
8 as follows:

Sec. 1. Short title and table of contents.

**TITLE I—PROHIBITION OF HEALTH INSURANCE DISCRIMINATION
ON THE BASIS OF PROTECTED GENETIC INFORMATION**

Sec. 101. Amendments to Employee Retirement Income Security Act of 1974.
Sec. 102. Amendments to the Public Health Service Act.
Sec. 103. Amendments to Internal Revenue Code of 1986.
Sec. 104. Amendments to Title XVIII of the Social Security Act relating to
Medigap.

**TITLE II—PROHIBITION OF EMPLOYMENT DISCRIMINATION ON
THE BASIS OF PROTECTED 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. Maintenance and disclosure of protected genetic information.
Sec. 207. Civil action.
Sec. 208. Exceptions; rules of construction.
Sec. 209. Authorization of appropriations.
Sec. 210. Effective date.

TITLE III—MISCELLANEOUS PROVISIONS

Sec. 301. Severability.

1 **TITLE I—PROHIBITION OF**
2 **HEALTH INSURANCE DIS-**
3 **CRIMINATION ON THE BASIS**
4 **OF PROTECTED GENETIC IN-**
5 **FORMATION**

6 **SEC. 101. AMENDMENTS TO EMPLOYEE RETIREMENT IN-**
7 **COME SECURITY ACT OF 1974.**

8 (a) PROHIBITION OF HEALTH INSURANCE DISCRIMI-
9 NATION ON THE BASIS OF GENETIC SERVICES OR PRO-
10 TECTED GENETIC INFORMATION.—

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

18 (2) NO DISCRIMINATION IN GROUP RATE BASED
19 ON PROTECTED GENETIC INFORMATION.—

20 (A) IN GENERAL.—Subpart B of part 7 of
21 subtitle B of title I of the Employee Retirement
22 Income Security Act of 1974 (29 U.S.C. 1185
23 et seq.) is amended by adding at the end the
24 following:

1 **“SEC. 714. PROHIBITING DISCRIMINATION AGAINST**
2 **GROUPS ON THE BASIS OF PROTECTED GE-**
3 **NETIC INFORMATION.**

4 “A group health plan, and a health insurance issuer
5 offering group health insurance coverage in connection
6 with a group health plan, shall not deny eligibility to a
7 group or adjust premium or contribution rates for a group
8 on the basis of protected genetic information concerning
9 an individual in the group (or information about a request
10 for or the receipt of genetic services by such individual
11 or family member of such individual).”.

12 (B) CONFORMING AMENDMENTS.—

13 (i) Section 702(b)(2)(A) of the Em-
14 ployee Retirement Income Security Act of
15 1974 (29 U.S.C. 1182(b)) is amended to
16 read as follows:

17 “(A) to restrict the amount that an em-
18 ployer may be charged for coverage under a
19 group health plan, except as provided in section
20 714; or”.

21 (ii) Section 732(a) of the Employee
22 Retirement Income Security Act of 1974
23 (29 U.S.C. 1191a(a)) is amended by strik-
24 ing “section 711” and inserting “sub-
25 sections (a)(1)(F), (b) (with respect to
26 cases relating to genetic information or in-

1 formation about a request or receipt of ge-
2 netic services by an individual or family
3 member of such individual), (c), (d), (e),
4 (f), or (g) of section 702, section 711 and
5 section 714”.

6 (b) LIMITATIONS ON GENETIC TESTING AND ON
7 COLLECTION AND DISCLOSURE OF PROTECTED GENETIC
8 INFORMATION.—Section 702 of the Employee Retirement
9 Income Security Act of 1974 (29 U.S.C. 1182) is amended
10 by adding at the end the following:

11 “(c) GENETIC TESTING.—

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

18 “(2) RULE OF CONSTRUCTION.—Nothing in
19 this part shall be construed to limit the authority of
20 a health care professional, who is providing treat-
21 ment with respect to an individual and who is em-
22 ployed by a group health plan or a health insurance
23 issuer, to request that such individual or family
24 member of such individual undergo a genetic test.
25 Such a health care professional shall not require

1 that such individual or family member undergo a ge-
2 netic test.

3 “(3) CERTAIN TESTS.—The conducting of met-
4 abolic tests that are not intended to reveal protected
5 genetic information shall not be considered a viola-
6 tion of the preceding provisions of this subsection re-
7 gardless of the results of the tests. Test results that
8 are protected genetic information shall be subject to
9 the applicable provisions of this part.

10 “(d) COLLECTION OF PROTECTED GENETIC INFOR-
11 MATION.—Except as provided in subsections (f) and (g),
12 a group health plan, or a health insurance issuer offering
13 health insurance coverage in connection with a group
14 health plan, shall not request, require, collect, or purchase
15 protected genetic information concerning an individual (or
16 information about a request for or the receipt of genetic
17 services by such individual or family member of such indi-
18 vidual).

19 “(e) DISCLOSURE OF PROTECTED GENETIC INFOR-
20 MATION.—A group health plan, or a health insurance
21 issuer offering health insurance coverage in connection
22 with a group health plan, shall not disclose protected ge-
23 netic information about an individual (or information
24 about a request for or the receipt of genetic services by
25 such individual or family member of such individual) to—

1 “(1) any entity that is a member of the same
2 controlled group as such issuer or plan sponsor of
3 such group health plan;

4 “(2) any other group health plan or health in-
5 surance issuer or any insurance agent, third party
6 administrator, or other person subject to regulation
7 under State insurance laws;

8 “(3) the Medical Information Bureau or any
9 other person that collects, compiles, publishes, or
10 otherwise disseminates insurance information;

11 “(4) the individual’s employer or any plan spon-
12 sor; or

13 “(5) any other person the Secretary may speci-
14 fy in regulations.

15 “(f) INFORMATION FOR PAYMENT FOR GENETIC
16 SERVICES.—

17 “(1) IN GENERAL.—With respect to payment
18 for genetic services conducted concerning an indi-
19 vidual or the coordination of benefits, a group health
20 plan, or a health insurance issuer offering group
21 health insurance coverage in connection with a group
22 health plan, may request that the individual provide
23 the plan or issuer with evidence that such services
24 were performed.

1 “(2) RULE OF CONSTRUCTION.—Nothing in
2 paragraph (1) shall be construed to—

3 “(A) permit a group health plan or health
4 insurance issuer to request (or require) the re-
5 sults of the services referred to in such para-
6 graph; or

7 “(B) require that a group health plan or
8 health insurance issuer make payment for serv-
9 ices described in such paragraph where the in-
10 dividual involved has refused to provide evi-
11 dence of the performance of such services pur-
12 suant to a request by the plan or issuer in ac-
13 cordance with such paragraph.

14 “(g) INFORMATION FOR PAYMENT OF OTHER
15 CLAIMS.—With respect to the payment of claims for bene-
16 fits other than genetic services, a group health plan, or
17 a health insurance issuer offering group health insurance
18 coverage in connection with a group health plan, may re-
19 quest that an individual provide protected genetic informa-
20 tion so long as such information—

21 “(1) is used solely for the payment of a claim;

22 “(2) is limited to information that is directly re-
23 lated to and necessary for the payment of such claim
24 and the claim would otherwise be denied but for the
25 protected genetic information; and

1 “(3) is used only by an individual (or individ-
2 uals) within such plan or issuer who needs access to
3 such information for purposes of payment of a
4 claim.

5 “(h) RULES OF CONSTRUCTION.—

6 “(1) COLLECTION OR DISCLOSURE AUTHORIZED
7 BY INDIVIDUAL.—The provisions of subsections (d)
8 (regarding collection) and (e) shall not apply to an
9 individual if the individual (or legal representative of
10 the individual) provides prior, knowing, voluntary,
11 and written authorization for the collection or disclo-
12 sure of protected genetic information.

13 “(2) DISCLOSURE FOR HEALTH CARE TREAT-
14 MENT.—Nothing in this section shall be construed to
15 limit or restrict the disclosure of protected genetic
16 information from a health care provider to another
17 health care provider for the purpose of providing
18 health care treatment to the individual involved.

19 “(i) DEFINITIONS.—In this section:

20 “(1) CONTROLLED GROUP.—The term ‘con-
21 trolled group’ means any group treated as a single
22 employer under subsection (b), (c), (m), or (o) of
23 section 414 of the Internal Revenue Code of 1986.

24 “(2) GROUP HEALTH PLAN, HEALTH INSUR-
25 ANCE ISSUER.—The terms ‘group health plan’ and

1 ‘health insurance issuer’ include a third party ad-
2 ministrator or other person acting for or on behalf
3 of such plan or issuer.”.

4 (c) ENFORCEMENT.—Section 502 (29 U.S.C. 1132)
5 is amended by adding at the end the following:

6 “(n) VIOLATION OF GENETIC DISCRIMINATION OR
7 GENETIC DISCLOSURE PROVISIONS.—

8 “(1) IN GENERAL.—In any action under this
9 section against any administrator of a group health
10 plan, or health insurance issuer offering group
11 health insurance coverage in connection with a group
12 health plan (including any third party administrator
13 or other person acting for or on behalf of such plan
14 or issuer) alleging a violation of subsection
15 (a)(1)(F), (b) (with respect to cases relating to ge-
16 netic information or information about a request or
17 receipt of genetic services by an individual or family
18 member of such individual), (c), (d), (e), (f), or (g)
19 of section 702, or section 714, the court may award
20 any appropriate legal or equitable relief. Such relief
21 may include a requirement for the payment of attor-
22 ney’s fees and costs, including the costs of expert
23 witnesses.

24 “(2) CIVIL PENALTY.—In any action described
25 in paragraph (1), the Secretary may, to vindicate

1 the public interest, assess a civil penalty against the
2 defendant in an amount—

3 “(A) not exceeding \$50,000 for a first vio-
4 lation, and

5 “(B) not exceeding \$100,000 for any sub-
6 sequent violation.

7 Any such relief awarded shall be paid into the gen-
8 eral fund of the Treasury.”.

9 (d) PREEMPTION.—Section 731 of the Employee Re-
10 tirement Income Security Act of 1974 (29 U.S.C. 1191)
11 is amended—

12 (1) in subsection (a)(1), by inserting “or (e)”
13 after “subsection (b)”; and

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

15 “(e) SPECIAL RULE IN CASE OF GENETIC INFORMA-
16 TION.—With respect to group health insurance coverage
17 offered by a health insurance issuer, the provisions of this
18 part relating to genetic information (including information
19 about a request for or the receipt of genetic services by
20 an individual or a family member of such individual) shall
21 not be construed to supersede any provision of State law
22 which establishes, implements, or continues in effect a
23 standard, requirement, or remedy that more completely—

24 “(1) protects the confidentiality of genetic in-
25 formation (including information about a request for

1 or the receipt of genetic services by an individual or
2 a family member of such individual) or the privacy
3 of an individual or a family member of the individual
4 with respect to genetic information (including infor-
5 mation about a request for or the receipt of genetic
6 services by an individual or a family member of such
7 individual) than does this part; or

8 “(2) prohibits discrimination on the basis of ge-
9 netic information than does this part.”.

10 (e) DEFINITIONS.—Section 733(d) of the Employee
11 Retirement Income Security Act of 1974 (29 U.S.C.
12 1191b(d)) is amended by adding at the end the following:

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

15 “(A) the spouse of the individual;

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

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

22 “(6) GENETIC INFORMATION.—The term ‘ge-
23 netic information’ means information about genes,
24 gene products, or inherited characteristics that may
25 derive from an individual or a family member of

1 such individual (including information about a re-
2 quest for or the receipt of genetic services by such
3 individual or family member of such individual).

4 “(7) GENETIC SERVICES.—The term ‘genetic
5 services’ means health services, including genetic
6 tests, provided to obtain, assess, or interpret genetic
7 information for diagnostic and therapeutic purposes,
8 and for genetic education and counseling.

9 “(8) GENETIC TEST.—The term ‘genetic test’
10 means the analysis of human DNA, RNA, chro-
11 mosomes, proteins, or metabolites that detects
12 genotypes, mutations, or chromosomal changes.

13 “(9) PROTECTED GENETIC INFORMATION.—

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

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

19 “(ii) information about genetic tests
20 of family members of the individual; and

21 “(iii) information about the occur-
22 rence of a disease or disorder in family
23 members.

24 “(B) LIMITATIONS.—The term ‘protected
25 genetic information’ shall not include—

1 “(i) information about the sex or age
2 of the individual;

3 “(ii) information about chemical,
4 blood, or urine analyses of the individual,
5 unless these analyses are genetic tests; or

6 “(iii) information about physical
7 exams of the individual, and other informa-
8 tion that indicates the current health sta-
9 tus of the individual.”.

10 (f) AMENDMENT CONCERNING SUPPLEMENTAL EX-
11 CEPTED BENEFITS.—Section 732(c)(3) of the Employee
12 Retirement Income Security Act of 1974 (29 U.S.C.
13 1191a(c)(3)) is amended by inserting “, other than the
14 requirements of subsections (a)(1)(F), (b) (in cases relat-
15 ing to genetic information or information about a request
16 for or the receipt of genetic services by an individual or
17 a family member of such individual), (c), (d), (e), (f) and
18 (g) of section 702 and section 714,” after “The require-
19 ments of this part”.

20 (g) EFFECTIVE DATE.—

21 (1) IN GENERAL.—Except as provided in this
22 section, this section and the amendments made by
23 this section shall apply with respect to group health
24 plans for plan years beginning after October 1,
25 2005.

1 (2) SPECIAL RULE FOR COLLECTIVE BAR-
2 GAINING AGREEMENTS.—In the case of a group
3 health plan maintained pursuant to one or more col-
4 lective bargaining agreements between employee rep-
5 resentatives and one or more employers ratified be-
6 fore the date of the enactment of this Act, this sec-
7 tion and the amendments made by this section shall
8 not apply to plan years beginning before the later
9 of—

10 (A) the date on which the last of the col-
11 lective bargaining agreements relating to the
12 plan terminates (determined without regard to
13 any extension thereof agreed to after the date
14 of the enactment of this Act), or

15 (B) October 1, 2005.

16 For purposes of subparagraph (A), any plan amend-
17 ment made pursuant to a collective bargaining
18 agreement relating to the plan which amends the
19 plan solely to conform to any requirement of the
20 amendments made by this section shall not be treat-
21 ed as a termination of such collective bargaining
22 agreement.

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

2 **ACT.**

3 (a) AMENDMENTS RELATING TO THE GROUP MAR-
4 KET.—

5 (1) PROHIBITION OF HEALTH INSURANCE DIS-
6 CRIMINATION ON THE BASIS OF PROTECTED GE-
7 NETIC INFORMATION OR GENETIC SERVICES.—

8 (A) NO ENROLLMENT RESTRICTION FOR
9 GENETIC SERVICES.—Section 2702(a)(1)(F) of
10 the Public Health Service Act (42 U.S.C.
11 300gg–1(a)(1)(F)) is amended by inserting be-
12 fore the period the following: “(or information
13 about a request for or the receipt of genetic
14 services by an individual or a family member of
15 such individual)”.

16 (B) NO DISCRIMINATION IN GROUP RATE
17 BASED ON PROTECTED GENETIC INFORMA-
18 TION.—

19 (i) IN GENERAL.—Subpart 2 of part
20 A of title XXVII of the Public Health
21 Service (42 U.S.C. 300gg–4 et seq.) is
22 amended by adding at the end the fol-
23 lowing:

1 **“SEC. 2707. PROHIBITING DISCRIMINATION AGAINST**
2 **GROUPS ON THE BASIS OF PROTECTED GE-**
3 **NETIC INFORMATION.**

4 “A group health plan, and a health insurance issuer
5 offering group health insurance coverage in connection
6 with a group health plan, shall not deny eligibility to a
7 group or adjust premium or contribution rates for a group
8 on the basis of protected genetic information concerning
9 an individual in the group (or information about a request
10 for or the receipt of genetic services by such individual
11 or family member of such individual).”.

12 (ii) CONFORMING AMENDMENTS.—

13 (I) Section 2702(b)(2)(A) of the
14 Public Health Service Act (42 U.S.C.
15 300gg-1(b)(2)(A)) is amended to read
16 as follows:

17 “(A) to restrict the amount that an em-
18 ployer may be charged for coverage under a
19 group health plan, except as provided in section
20 2707; or”.

21 (II) Section 2721(a) of the Pub-
22 lic Health Service Act (42 U.S.C.
23 300gg-21(a)) is amended by inserting
24 “(other than subsections (a)(1)(F),
25 (b) (with respect to cases relating to
26 genetic information or information

1 about a request or receipt of genetic
2 services by an individual or family
3 member of such individual), (c), (d),
4 (e), (f), or (g) of section 2702 and
5 section 2707)” after “subparts 1 and
6 3”.

7 (2) LIMITATIONS ON GENETIC TESTING AND ON
8 COLLECTION AND DISCLOSURE OF PROTECTED GE-
9 NETIC INFORMATION.—Section 2702 of the Public
10 Health Service Act (42 U.S.C. 300gg–1) is amended
11 by adding at the end the following:

12 “(c) GENETIC TESTING.—

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

19 “(2) RULE OF CONSTRUCTION.—Nothing in
20 this title shall be construed to limit the authority of
21 a health care professional, who is providing treat-
22 ment with respect to an individual and who is em-
23 ployed by a group health plan or a health insurance
24 issuer, to request that such individual or family
25 member of such individual undergo a genetic test.

1 Such a health care professional shall not require
2 that such individual or family member undergo a ge-
3 netic test.

4 “(3) CERTAIN TESTS.—The conducting of met-
5 abolic tests that are not intended to reveal protected
6 genetic information shall not be considered a viola-
7 tion of the preceding provisions of this subsection re-
8 gardless of the results of the tests. Test results that
9 are protected genetic information shall be subject to
10 the applicable provisions of this title.

11 “(d) COLLECTION OF PROTECTED GENETIC INFOR-
12 MATION.—Except as provided in subsections (f) and (g),
13 a group health plan, or a health insurance issuer offering
14 health insurance coverage in connection with a group
15 health plan, shall not request, require, collect, or purchase
16 protected genetic information concerning an individual (or
17 information about a request for or the receipt of genetic
18 services by such individual or family member of such indi-
19 vidual).

20 “(e) DISCLOSURE OF PROTECTED GENETIC INFOR-
21 MATION.—A group health plan, or a health insurance
22 issuer offering health insurance coverage in connection
23 with a group health plan, shall not disclose protected ge-
24 netic information about an individual (or information

1 about a request for or the receipt of genetic services by
2 such individual or family member of such individual) to—

3 “(1) any entity that is a member of the same
4 controlled group as such issuer or plan sponsor of
5 such group health plan;

6 “(2) any other group health plan or health in-
7 surance issuer or any insurance agent, third party
8 administrator, or other person subject to regulation
9 under State insurance laws;

10 “(3) the Medical Information Bureau or any
11 other person that collects, compiles, publishes, or
12 otherwise disseminates insurance information;

13 “(4) the individual’s employer or any plan spon-
14 sor; or

15 “(5) any other person the Secretary may speci-
16 fy in regulations.

17 “(f) INFORMATION FOR PAYMENT FOR GENETIC
18 SERVICES.—

19 “(1) IN GENERAL.—With respect to payment
20 for genetic services conducted concerning an indi-
21 vidual or the coordination of benefits, a group health
22 plan, or a health insurance issuer offering group
23 health insurance coverage in connection with a group
24 health plan, may request that the individual provide

1 the plan or issuer with evidence that such services
2 were performed.

3 “(2) RULE OF CONSTRUCTION.—Nothing in
4 paragraph (1) shall be construed to—

5 “(A) permit a group health plan or health
6 insurance issuer to request (or require) the re-
7 sults of the services referred to in such para-
8 graph; or

9 “(B) require that a group health plan or
10 health insurance issuer make payment for serv-
11 ices described in such paragraph where the in-
12 dividual involved has refused to provide evi-
13 dence of the performance of such services pur-
14 suant to a request by the plan or issuer in ac-
15 cordance with such paragraph.

16 “(g) INFORMATION FOR PAYMENT OF OTHER
17 CLAIMS.—With respect to the payment of claims for bene-
18 fits other than genetic services, a group health plan, or
19 a health insurance issuer offering group health insurance
20 coverage in connection with a group health plan, may re-
21 quest that an individual provide protected genetic informa-
22 tion so long as such information—

23 “(1) is used solely for the payment of a claim;

24 “(2) is limited to information that is directly re-
25 lated to and necessary for the payment of such claim

1 and the claim would otherwise be denied but for the
2 protected genetic information; and

3 “(3) is used only by an individual (or individ-
4 uals) within such plan or issuer who needs access to
5 such information for purposes of payment of a
6 claim.

7 “(h) RULES OF CONSTRUCTION.—

8 “(1) COLLECTION OR DISCLOSURE AUTHORIZED
9 BY INDIVIDUAL.—The provisions of subsections (d)
10 (regarding collection) and (e) shall not apply to an
11 individual if the individual (or legal representative of
12 the individual) provides prior, knowing, voluntary,
13 and written authorization for the collection or disclo-
14 sure of protected genetic information.

15 “(2) DISCLOSURE FOR HEALTH CARE TREAT-
16 MENT.—Nothing in this section shall be construed to
17 limit or restrict the disclosure of protected genetic
18 information from a health care provider to another
19 health care provider for the purpose of providing
20 health care treatment to the individual involved.

21 “(i) DEFINITIONS.—In this section:

22 “(1) CONTROLLED GROUP.—The term ‘con-
23 trolled group’ means any group treated as a single
24 employer under subsection (b), (c), (m), or (o) of
25 section 414 of the Internal Revenue Code of 1986.

1 “(2) GROUP HEALTH PLAN, HEALTH INSUR-
2 ANCE ISSUER.—The terms ‘group health plan’ and
3 ‘health insurance issuer’ include a third party ad-
4 ministrators or other person acting for or on behalf
5 of such plan or issuer.”.

6 (3) DEFINITIONS.—Section 2791(d) of the Pub-
7 lic Health Service Act (42 U.S.C. 300gg–91(d)) is
8 amended by adding at the end the following new
9 paragraphs:

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

12 “(A) the spouse of the individual;

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

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

19 “(16) GENETIC INFORMATION.—The term ‘ge-
20 netic information’ means information about genes,
21 gene products, or inherited characteristics that may
22 derive from an individual or a family member of
23 such individual (including information about a re-
24 quest for or the receipt of genetic services by such
25 individual or family member of such individual).

1 “(17) GENETIC SERVICES.—The term ‘genetic
2 services’ means health services, including genetic
3 tests, provided to obtain, assess, or interpret genetic
4 information for diagnostic and therapeutic purposes,
5 and for genetic education and counselling.

6 “(18) GENETIC TEST.—The term ‘genetic test’
7 means the analysis of human DNA, RNA, chro-
8 mosomes, proteins, or metabolites that detects
9 genotypes, mutations, or chromosomal changes.

10 “(19) PROTECTED GENETIC INFORMATION.—

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

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

16 “(ii) information about genetic tests
17 of family members of the individual; and

18 “(iii) information about the occur-
19 rence of a disease or disorder in family
20 members.”.

21 “(B) LIMITATIONS.—The term ‘protected
22 genetic information’ shall not include—

23 “(i) information about the sex or age
24 of the individual;

1 “(ii) information about chemical,
2 blood, or urine analyses of the individual,
3 unless these analyses are genetic tests; or

4 “(iii) information about physical
5 exams of the individual, and other informa-
6 tion that indicates the current health sta-
7 tus of the individual.”.

8 (b) AMENDMENT RELATING TO THE INDIVIDUAL
9 MARKET.—The first subpart 3 of part B of title XXVII
10 of the Public Health Service Act (42 U.S.C. 300gg–51 et
11 seq.) is amended—

12 (1) by redesignating such subpart as subpart 2;

13 and

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

15 **“SEC. 2753. PROHIBITION OF HEALTH INSURANCE DIS-**
16 **CRIMINATION AGAINST INDIVIDUALS ON THE**
17 **BASIS OF PROTECTED GENETIC INFORMA-**
18 **TION.**

19 “(a) INELIGIBILITY TO ENROLL.—A health insur-
20 ance issuer offering health insurance coverage in the indi-
21 vidual market shall not establish rules for eligibility to en-
22 roll in individual health insurance coverage that are based
23 on protected genetic information concerning the individual
24 (or information about a request for or the receipt of ge-

1 netic services by such individual or family member of such
2 individual).

3 “(b) IN PREMIUM RATES.—A health insurance issuer
4 offering health insurance coverage in the individual mar-
5 ket shall not adjust premium rates on the basis of pro-
6 tected genetic information concerning an individual (or in-
7 formation about a request for or the receipt of genetic
8 services by such individual or family member of such indi-
9 vidual).

10 **“SEC. 2754. LIMITATIONS ON GENETIC TESTING AND ON**
11 **COLLECTION AND DISCLOSURE OF PRO-**
12 **TECTED GENETIC INFORMATION.**

13 “(a) GENETIC TESTING.—

14 “(1) LIMITATION ON REQUESTING OR REQUIR-
15 ING GENETIC TESTING.—A health insurance issuer
16 offering health insurance coverage in the individual
17 market shall not request or require an individual or
18 a family member of such individual to undergo a ge-
19 netic test.

20 “(2) RULE OF CONSTRUCTION.—Nothing in
21 this title shall be construed to limit the authority of
22 a health care professional, who is providing treat-
23 ment with respect to an individual and who is em-
24 ployed by a group health plan or a health insurance
25 issuer, to request that such individual or family

1 member of such individual undergo a genetic test.
2 Such a health care professional shall not require
3 that such individual or family member undergo a ge-
4 netic test.

5 “(3) CERTAIN TESTS.—The conducting of met-
6 abolic tests that are not intended to reveal protected
7 genetic information shall not be considered a viola-
8 tion of the preceding provisions of this subsection re-
9 gardless of the results of the tests. Test results that
10 are protected genetic information shall be subject to
11 the applicable provisions of this title.

12 “(b) COLLECTION OF PROTECTED GENETIC INFOR-
13 MATION.—Except as provided in subsections (d) and (e),
14 a health insurance issuer offering health insurance cov-
15 erage in the individual market shall not request, require,
16 collect, or purchase protected genetic information con-
17 cerning an individual (or information about a request for
18 or the receipt of genetic services by such individual or fam-
19 ily member of such individual).

20 “(c) DISCLOSURE OF PROTECTED GENETIC INFOR-
21 MATION.—A health insurance issuer offering health insur-
22 ance coverage in the individual market shall not disclose
23 protected genetic information about an individual (or in-
24 formation about a request for or the receipt of genetic

1 services by such individual or family member of such indi-
2 vidual) to—

3 “(1) any entity that is a member of the same
4 controlled group as such issuer or plan sponsor of
5 such group health plan;

6 “(2) any other group health plan or health in-
7 surance issuer or any insurance agent, third party
8 administrator, or other person subject to regulation
9 under State insurance laws;

10 “(3) the Medical Information Bureau or any
11 other person that collects, compiles, publishes, or
12 otherwise disseminates insurance information;

13 “(4) the individual’s employer or any plan spon-
14 sor; or

15 “(5) any other person the Secretary may speci-
16 fy in regulations.

17 “(d) INFORMATION FOR PAYMENT FOR GENETIC
18 SERVICES.—

19 “(1) IN GENERAL.—With respect to payment
20 for genetic services conducted concerning an indi-
21 vidual or the coordination of benefits, a health insur-
22 ance issuer offering health insurance coverage in the
23 individual market may request that the individual
24 provide the plan or issuer with evidence that such
25 services were performed.

1 “(2) RULE OF CONSTRUCTION.—Nothing in
2 paragraph (1) shall be construed to—

3 “(A) permit a health insurance issuer to
4 request (or require) the results of the services
5 referred to in such paragraph; or

6 “(B) require that a health insurance issuer
7 make payment for services described in such
8 paragraph where the individual involved has re-
9 fused to provide evidence of the performance of
10 such services pursuant to a request by the plan
11 or issuer in accordance with such paragraph.

12 “(e) INFORMATION FOR PAYMENT OF OTHER
13 CLAIMS.—With respect to the payment of claims for bene-
14 fits other than genetic services, a health insurance issuer
15 offering health insurance coverage in the individual mar-
16 ket may request that an individual provide protected ge-
17 netic information so long as such information—

18 “(1) is used solely for the payment of a claim;

19 “(2) is limited to information that is directly re-
20 lated to and necessary for the payment of such claim
21 and the claim would otherwise be denied but for the
22 protected genetic information; and

23 “(3) is used only by an individual (or individ-
24 uals) within such plan or issuer who needs access to

1 such information for purposes of payment of a
2 claim.

3 “(f) RULES OF CONSTRUCTION.—

4 “(1) COLLECTION OR DISCLOSURE AUTHORIZED
5 BY INDIVIDUAL.—The provisions of subsections (c)
6 (regarding collection) and (d) shall not apply to an
7 individual if the individual (or legal representative of
8 the individual) provides prior, knowing, voluntary,
9 and written authorization for the collection or disclo-
10 sure of protected genetic information.

11 “(2) DISCLOSURE FOR HEALTH CARE TREAT-
12 MENT.—Nothing in this section shall be construed to
13 limit or restrict the disclosure of protected genetic
14 information from a health care provider to another
15 health care provider for the purpose of providing
16 health care treatment to the individual involved.

17 “(g) DEFINITIONS.—In this section:

18 “(1) CONTROLLED GROUP.—The term ‘con-
19 trolled group’ means any group treated as a single
20 employer under subsection (b), (c), (m), or (o) of
21 section 414 of the Internal Revenue Code of 1986.

22 “(2) GROUP HEALTH PLAN, HEALTH INSUR-
23 ANCE ISSUER.—The terms ‘group health plan’ and
24 ‘health insurance issuer’ include a third party ad-

1 administrator or other person acting for or on behalf
2 of such plan or issuer.”.

3 (c) ENFORCEMENT.—

4 (1) GROUP PLANS.—Section 2722 of the Public
5 Health Service Act (42 U.S.C. 300gg–22) is amend-
6 ed by adding at the end the following:

7 “(c) VIOLATION OF GENETIC DISCRIMINATION OR
8 GENETIC DISCLOSURE PROVISIONS.—

9 “(1) IN GENERAL.—In any action under this
10 section against any administrator of a group health
11 plan, or health insurance issuer offering group
12 health insurance coverage in connection with a group
13 health plan (including any third party administrator
14 or other person acting for or on behalf of such plan
15 or issuer) alleging a violation of subsections
16 (a)(1)(F), (b) (with respect to cases relating to ge-
17 netic information or information about a request or
18 receipt of genetic services by an individual or family
19 member of such individual), (c), (d), (e), (f), or (g)
20 of section 2702 and section 2707 the court may
21 award any appropriate legal or equitable relief. Such
22 relief may include a requirement for the payment of
23 attorney’s fees and costs, including the costs of ex-
24 pert witnesses.

1 “(2) CIVIL PENALTY.—In any action described
2 in paragraph (1), the Secretary may, to vindicate
3 the public interest, assess a civil penalty against the
4 defendant in an amount—

5 “(A) not exceeding \$50,000 for a first vio-
6 lation, and

7 “(B) not exceeding \$100,000 for any sub-
8 sequent violation.

9 Any such relief awarded shall be paid into the gen-
10 eral fund of the Treasury.”.

11 (2) INDIVIDUAL PLANS.—Section 2761 of the
12 Public Health Service Act (42 U.S.C. 300gg-45) is
13 amended by adding at the end the following:

14 “(c) VIOLATION OF GENETIC DISCRIMINATION OR
15 GENETIC DISCLOSURE PROVISIONS.—

16 “(1) IN GENERAL.—In any action under this
17 section against any health insurance issuer offering
18 health insurance coverage in the individual market
19 (including any other person acting for or on behalf
20 of such issuer) alleging a violation of sections 2753
21 and 2754 the court in which the action is com-
22 menced may award any appropriate legal or equi-
23 table relief. Such relief may include a requirement
24 for the payment of attorney’s fees and costs, includ-
25 ing the costs of expert witnesses.

1 “(2) CIVIL PENALTY.—In any action described
2 in paragraph (1), the Secretary may, to vindicate
3 the public interest, assess a civil penalty against the
4 defendant in an amount—

5 “(A) not exceeding \$50,000 for a first vio-
6 lation, and

7 “(B) not exceeding \$100,000 for any sub-
8 sequent violation.

9 Any such relief awarded shall be paid into the gen-
10 eral fund of the Treasury.”.

11 (d) PREEMPTION.—

12 (1) GROUP MARKET.—Section 2723 of the Pub-
13 lic Health Service Act (42 U.S.C. 300gg-23) is
14 amended—

15 (A) in subsection (a)(1), by inserting “or
16 (e)” after “subsection (b)”; and

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

18 “(e) SPECIAL RULE IN CASE OF GENETIC INFORMA-
19 TION.—With respect to group health insurance coverage
20 offered by a health insurance issuer, the provisions of this
21 part relating to genetic information (including information
22 about a request for or the receipt of genetic services by
23 an individual or a family member of such individual) shall
24 not be construed to supersede any provision of State law

1 which establishes, implements, or continues in effect a
2 standard, requirement, or remedy that more completely—

3 “(1) protects the confidentiality of genetic in-
4 formation (including information about a request for
5 or the receipt of genetic services by an individual or
6 a family member of such individual) or the privacy
7 of an individual or a family member of the individual
8 with respect to genetic information (including infor-
9 mation about a request for or the receipt of genetic
10 services by an individual or a family member of such
11 individual) than does this part; or

12 “(2) prohibits discrimination on the basis of ge-
13 netic information than does this part.”.

14 (2) INDIVIDUAL MARKET.—Section 2762 of the
15 Public Health Service Act (42 U.S.C. 300gg–46) is
16 amended—

17 (A) in subsection (a), by inserting “and ex-
18 cept as provided in subsection (c),” after “Sub-
19 ject to subsection (b),”; and

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

21 “(c) SPECIAL RULE IN CASE OF GENETIC INFORMA-
22 TION.—With respect to individual health insurance cov-
23 erage offered by a health insurance issuer, the provisions
24 of this part (or part C insofar as it applies to this part)
25 relating to genetic information (including information

1 about a request for or the receipt of genetic services by
2 an individual or a family member of such individual) shall
3 not be construed to supersede any provision of State law
4 (as defined in section 2723(d)) which establishes, imple-
5 ments, or continues in effect a standard, requirement, or
6 remedy that more completely—

7 “(1) protects the confidentiality of genetic in-
8 formation (including information about a request for
9 or the receipt of genetic services of an individual or
10 a family member of such individual) or the privacy
11 of an individual or a family member of the individual
12 with respect to genetic information (including infor-
13 mation about a request for or the receipt of genetic
14 services by an individual or a family member of such
15 individual) than does this part (or part C insofar as
16 it applies to this part); or

17 “(2) prohibits discrimination on the basis of ge-
18 netic information than does this part (or part C in-
19 sofar as it applies to this part).”.

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

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

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

5 “(D) ELECTION NOT APPLICABLE TO RE-
6 QUIREMENTS CONCERNING GENETIC INFORMA-
7 TION.—The election described in subparagraph
8 (A) shall not be available with respect to the
9 provisions of subsections (a)(1)(F), (c), (d), (e),
10 (f), and (g) of section 2702 and section 2707,
11 and the provisions of section 2702(b) to the ex-
12 tent that they apply to genetic information (or
13 information about a request for or the receipt
14 of genetic services by an individual or a family
15 member of such individual).”.

16 (f) AMENDMENT CONCERNING SUPPLEMENTAL EX-
17 CEPTED BENEFITS.—

18 (1) GROUP MARKET.—Section 2721(d)(3) of
19 the Public Health Service Act (42 U.S.C. 300gg-
20 23(d)(3)) is amended by inserting “, other than the
21 requirements of subsections (a)(1)(F), (b) (in cases
22 relating to genetic information or information about
23 a request for or the receipt of genetic services by an
24 individual or a family member of such individual)),

1 (c), (d), (e), (f) and (g) of section 2702 and section
2 2707,” after “The requirements of this part”.

3 (2) INDIVIDUAL MARKET.—Section 2763(b) of
4 the Public Health Service Act (42 U.S.C. 300gg–
5 47(b)) is amended—

6 (A) by striking “The requirements of this
7 part” and inserting the following:

8 “(1) IN GENERAL.—Except as provided in para-
9 graph (2), the requirements of this part”; and

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

11 “(2) LIMITATION.—The requirements of sec-
12 tions 2753 and 2754 shall apply to excepted benefits
13 described in section 2791(c)(4).”.

14 (g) EFFECTIVE DATE.—

15 (1) IN GENERAL.—The amendments made by
16 this section shall apply with respect to—

17 (A) group health plans, and health insur-
18 ance coverage offered in connection with group
19 health plans, for plan years beginning; and

20 (B) health insurance coverage offered,
21 sold, issued, renewed, in effect, or operated in
22 the individual market, after;

23 October 1, 2005.

24 (2) SPECIAL RULE FOR COLLECTIVE BAR-
25 GAINING AGREEMENTS.—In the case of a group

1 health plan maintained pursuant to one or more col-
2 lective bargaining agreements between employee rep-
3 resentatives and one or more employers ratified be-
4 fore the date of the enactment of this Act, the
5 amendments made by this section shall not apply to
6 plan years beginning before the later of—

7 (A) the date on which the last of the col-
8 lective bargaining agreements relating to the
9 plan terminates (determined without regard to
10 any extension thereof agreed to after the date
11 of the enactment of this Act); or

12 (B) October 1, 2005.

13 For purposes of subparagraph (A), any plan amend-
14 ment made pursuant to a collective bargaining
15 agreement relating to the plan which amends the
16 plan solely to conform to any requirement of the
17 amendments made by this section shall not be treat-
18 ed as a termination of such collective bargaining
19 agreement.

20 **SEC. 103. AMENDMENTS TO INTERNAL REVENUE CODE OF**
21 **1986.**

22 (a) PROHIBITION OF HEALTH INSURANCE DISCRIMI-
23 NATION ON THE BASIS OF GENETIC SERVICES OR PRO-
24 TECTED GENETIC INFORMATION.—

1 (1) NO ENROLLMENT RESTRICTION FOR GE-
2 NETIC SERVICES.—Section 9802(a)(1)(F) of the In-
3 ternal Revenue Code of 1986 is amended by insert-
4 ing before the period “(or information about a re-
5 quest for or the receipt of genetic services by such
6 individual or family member of such individual)”.

7 (2) NO DISCRIMINATION IN GROUP RATE BASED
8 ON PROTECTED GENETIC INFORMATION.—

9 (A) IN GENERAL.—Subchapter B of chap-
10 ter 100 of the Internal Revenue Code of 1986
11 is amended by adding at the end the following:

12 **“SEC. 9813. PROHIBITING DISCRIMINATION AGAINST**
13 **GROUPS ON THE BASIS OF PROTECTED GE-**
14 **NETIC INFORMATION.**

15 “A group health plan shall not deny eligibility to a
16 group or adjust premium or contribution rates for a group
17 on the basis of protected genetic information concerning
18 an individual in the group (or information about a request
19 for or the receipt of genetic services by such individual
20 or family member of such individual).”.

21 (B) CONFORMING AMENDMENTS.—

22 (i) Section 9802(b)(2)(A) of the Inter-
23 nal Revenue Code of 1986 is amended to
24 read as follows:

1 “(A) to restrict the amount that an em-
2 ployer may be charged for coverage under a
3 group health plan, except as provided in section
4 9813; or”.

5 (ii) Section 9831(a) of the Internal
6 Revenue Code of 1986 is amended by in-
7 serting “(other than subsections (a)(1)(F),
8 (b) (with respect to cases relating to ge-
9 netic information or information about a
10 request or receipt of genetic services by an
11 individual or family member of such indi-
12 vidual), (d), (e), (f), (g), or (h) of section
13 9802 or section 9813) after “chapter”.

14 (b) LIMITATIONS ON GENETIC TESTING AND ON
15 COLLECTION AND DISCLOSURE OF PROTECTED GENETIC
16 INFORMATION.—Section 9802 of the Internal Revenue
17 Code of 1986 is amended by adding at the end the fol-
18 lowing:

19 “(d) GENETIC TESTING.—

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

24 “(2) RULE OF CONSTRUCTION.—Nothing in
25 this chapter shall be construed to limit the authority

1 of a health care professional, who is providing treat-
2 ment with respect to an individual and who is em-
3 ployed by a group health plan, to request that such
4 individual or family member of such individual un-
5 dergo a genetic test. Such a health care professional
6 shall not require that such individual or family mem-
7 ber undergo a genetic test.

8 “(3) CERTAIN TESTS.—The conducting of met-
9 abolic tests that are not intended to reveal protected
10 genetic information shall not be considered a viola-
11 tion of the preceding provisions of this subsection re-
12 gardless of the results of the tests. Test results that
13 are protected genetic information shall be subject to
14 the applicable provisions of this chapter.

15 “(e) COLLECTION OF PROTECTED GENETIC INFOR-
16 MATION.—Except as provided in subsections (g) and (h),
17 a group health plan shall not request, require, collect, or
18 purchase protected genetic information concerning an in-
19 dividual (or information about a request for or the receipt
20 of genetic services by such individual or family member
21 of such individual).

22 “(f) DISCLOSURE OF PROTECTED GENETIC INFOR-
23 MATION.—A group health plan shall not disclose protected
24 genetic information about an individual (or information

1 about a request for or the receipt of genetic services by
2 such individual or family member of such individual) to—

3 “(1) any entity that is a member of the same
4 controlled group as such issuer or plan sponsor of
5 such group health plan;

6 “(2) any other group health plan or health in-
7 surance issuer or any insurance agent, third party
8 administrator, or other person subject to regulation
9 under State insurance laws;

10 “(3) the Medical Information Bureau or any
11 other person that collects, compiles, publishes, or
12 otherwise disseminates insurance information;

13 “(4) the individual’s employer or any plan spon-
14 sor; or

15 “(5) any other person the Secretary may speci-
16 fy in regulations.

17 “(g) INFORMATION FOR PAYMENT FOR GENETIC
18 SERVICES.—

19 “(1) IN GENERAL.—With respect to payment
20 for genetic services conducted concerning an indi-
21 vidual or the coordination of benefits, a group health
22 plan may request that the individual provide the
23 plan with evidence that such services were per-
24 formed.

1 “(2) RULE OF CONSTRUCTION.—Nothing in
2 paragraph (1) shall be construed to—

3 “(A) permit a group health plan to request
4 (or require) the results of the services referred
5 to in such paragraph; or

6 “(B) require that a group health plan
7 make payment for services described in such
8 paragraph where the individual involved has re-
9 fused to provide evidence of the performance of
10 such services pursuant to a request by the plan
11 in accordance with such paragraph.

12 “(h) INFORMATION FOR PAYMENT OF OTHER
13 CLAIMS.—With respect to the payment of claims for bene-
14 fits other than genetic services, a group health plan may
15 request that an individual provide protected genetic infor-
16 mation so long as such information—

17 “(1) is used solely for the payment of a claim;

18 “(2) is limited to information that is directly re-
19 lated to and necessary for the payment of such claim
20 and the claim would otherwise be denied but for the
21 protected genetic information; and

22 “(3) is used only by an individual (or individ-
23 uals) within such plan or issuer who needs access to
24 such information for purposes of payment of a
25 claim.

1 “(i) RULES OF CONSTRUCTION.—

2 “(1) COLLECTION OR DISCLOSURE AUTHORIZED
3 BY INDIVIDUAL.—The provisions of subsections (e)
4 (regarding collection) and (f) shall not apply to an
5 individual if the individual (or legal representative
6 of, the individual) provides prior, knowing, vol-
7 untary, and written authorization for the collection
8 or disclosure of protected genetic information.

9 “(2) DISCLOSURE FOR HEALTH CARE TREAT-
10 MENT.—Nothing in this section shall be construed to
11 limit or restrict the disclosure of protected genetic
12 information from a health care provider to another
13 health care provider for the purpose of providing
14 health care treatment to the individual involved.

15 “(j) DEFINITIONS.—In this section:

16 “(1) CONTROLLED GROUP.—The term ‘con-
17 trolled group’ means any group treated as a single
18 employer under subsections (b), (c), (m), or (o) of
19 section 414.

20 “(2) GROUP HEALTH PLAN, HEALTH INSUR-
21 ANCE ISSUER.—The terms ‘group health plan’ and
22 ‘health insurance issuer’ include a third party ad-
23 ministrator or other person acting for or on behalf
24 of such plan or issuer.”.

1 (c) DEFINITIONS.—Section 9832(d) of the Internal
2 Revenue Code of 1986 is amended by adding at the end
3 the following:

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

6 “(A) the spouse of the individual;

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

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

13 “(7) GENETIC INFORMATION.—The term ‘ge-
14 netic information’ means information about genes,
15 gene products, or inherited characteristics that may
16 derive from an individual or a family member of
17 such individual (including information about a re-
18 quest for or the receipt of genetic services by such
19 individual or family member of such individual).

20 “(8) GENETIC SERVICES.—The term ‘genetic
21 services’ means health services, including genetic
22 tests, provided to obtain, assess, or interpret genetic
23 information for diagnostic and therapeutic purposes,
24 and for genetic education and counseling.

1 “(9) GENETIC TEST.—The term ‘genetic test’
2 means the analysis of human DNA, RNA, chro-
3 mosomes, proteins, or metabolites that detects
4 genotypes, mutations, or chromosomal changes.

5 “(10) PROTECTED GENETIC INFORMATION.—

6 “(A) IN GENERAL.—Except as provided in
7 subparagraph (B), the term ‘protected genetic
8 information’ means—

9 “(i) information about an individual’s
10 genetic tests;

11 “(ii) information about genetic tests
12 of family members of the individual; and

13 “(iii) information about the occur-
14 rence of a disease or disorder in family
15 members.

16 “(B) LIMITATIONS.—The term ‘protected
17 genetic information’ shall not include—

18 “(i) information about the sex or age
19 of the individual;

20 “(ii) information about chemical,
21 blood, or urine analyses of the individual,
22 unless these analyses are genetic tests; or

23 “(iii) information about physical
24 exams of the individual, and other informa-

1 tion that indicates the current health sta-
2 tus of the individual.”.

3 (d) EFFECTIVE DATE.—

4 (1) IN GENERAL.—Except as provided in this
5 section, this section and the amendments made by
6 this section shall apply with respect to group health
7 plans for plan years beginning after October 1,
8 2005.

9 (2) SPECIAL RULE FOR COLLECTIVE BAR-
10 GAINING AGREEMENTS.—In the case of a group
11 health plan maintained pursuant to one or more col-
12 lective bargaining agreements between employee rep-
13 resentatives and one or more employers ratified be-
14 fore the date of the enactment of this Act, this sec-
15 tion and the amendments made by this section shall
16 not apply to plan years beginning before the later
17 of—

18 (A) the date on which the last of the col-
19 lective bargaining agreements relating to the
20 plan terminates (determined without regard to
21 any extension thereof agreed to after the date
22 of the enactment of this Act), or

23 (B) October 1, 2005.

24 For purposes of subparagraph (A), any plan amend-
25 ment made pursuant to a collective bargaining

1 agreement relating to the plan which amends the
2 plan solely to conform to any requirement of the
3 amendments made by this section shall not be treat-
4 ed as a termination of such collective bargaining
5 agreement.

6 **SEC. 104. AMENDMENTS TO TITLE XVIII OF THE SOCIAL SE-**
7 **CURITY ACT RELATING TO MEDIGAP.**

8 (a) NONDISCRIMINATION.—

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

12 “(E)(i) An issuer of a medicare supple-
13 mental policy shall not deny or condition the
14 issuance or effectiveness of the policy, and shall
15 not discriminate in the pricing of the policy (in-
16 cluding the adjustment of premium rates) of an
17 eligible individual on the basis of protected ge-
18 netic information concerning the individual (or
19 information about a request for, or the receipt
20 of, genetic services by such individual or family
21 member of such individual).

22 “(ii) For purposes of clause (i), the terms
23 ‘family member’, ‘genetic services’, and ‘pro-
24 tected genetic information’ shall have the mean-
25 ings given such terms in subsection (v).”.

1 (2) EFFECTIVE DATE.—The amendment made
2 by paragraph (1) shall apply with respect to a policy
3 for policy years beginning after October 1, 2005.

4 (b) LIMITATIONS ON GENETIC TESTING AND ON
5 COLLECTION AND DISCLOSURE OF PROTECTED GENETIC
6 INFORMATION.—

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

10 “(v) LIMITATIONS ON GENETIC TESTING AND ON
11 COLLECTION AND DISCLOSURE OF PROTECTED GENETIC
12 INFORMATION.—

13 “(1) GENETIC TESTING.—

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

19 “(B) RULE OF CONSTRUCTION.—Nothing
20 in this title shall be construed to limit the au-
21 thority of a health care professional, who is pro-
22 viding treatment with respect to an individual
23 and who is employed by an issuer of a medicare
24 supplemental policy, to request that such indi-
25 vidual or family member of such individual un-

1 dergo a genetic test. Such a health care profes-
2 sional shall not require that such individual or
3 family member undergo a genetic test.

4 “(C) CERTAIN TESTS.—The conducting of
5 metabolic tests that are not intended to reveal
6 protected genetic information shall not be con-
7 sidered a violation of the preceding provisions
8 of this paragraph regardless of the results of
9 the tests. Test results that are protected genetic
10 information shall be subject to the applicable
11 provisions of this subsection.

12 “(2) COLLECTION OF PROTECTED GENETIC IN-
13 FORMATION.—Except as provided in paragraphs (4)
14 and (5), an issuer of a medicare supplemental policy
15 shall not request, require, collect, or purchase pro-
16 tected genetic information concerning an individual
17 (or information about a request for or the receipt of
18 genetic services by such individual or family member
19 of such individual).

20 “(3) DISCLOSURE OF PROTECTED GENETIC IN-
21 FORMATION.—An issuer of a medicare supplemental
22 policy shall not disclose protected genetic informa-
23 tion about an individual (or information about a re-
24 quest for or the receipt of genetic services by such
25 individual or family member of such individual) to—

1 “(A) any entity that is a member of the
2 same controlled group as such issuer;

3 “(B) any issuer of a medicare supple-
4 mental policy, group health plan or health in-
5 surance issuer, or any insurance agent, third
6 party administrator, or other person subject to
7 regulation under State insurance laws;

8 “(C) the Medical Information Bureau or
9 any other person that collects, compiles, pub-
10 lishes, or otherwise disseminates insurance in-
11 formation;

12 “(D) the individual’s employer or any plan
13 sponsor; or

14 “(E) any other person the Secretary may
15 specify in regulations.

16 “(4) INFORMATION FOR PAYMENT FOR GE-
17 NETIC SERVICES.—

18 “(A) IN GENERAL.—With respect to pay-
19 ment for genetic services conducted concerning
20 an individual or the coordination of benefits, an
21 issuer of a medicare supplemental policy may
22 request that the individual provide the issuer
23 with evidence that such services were per-
24 formed.

1 “(B) RULE OF CONSTRUCTION.—Nothing
2 in subparagraph (A) shall be construed to—

3 “(i) permit an issuer to request (or
4 require) the results of the services referred
5 to in such subparagraph; or

6 “(ii) require that an issuer make pay-
7 ment for services described in such sub-
8 paragraph where the individual involved
9 has refused to provide evidence of the per-
10 formance of such services pursuant to a re-
11 quest by the issuer in accordance with such
12 subparagraph.

13 “(5) INFORMATION FOR PAYMENT OF OTHER
14 CLAIMS.—With respect to the payment of claims for
15 benefits other than genetic services, an issuer of a
16 medicare supplemental policy may request that an
17 individual provide protected genetic information so
18 long as such information—

19 “(A) is used solely for the payment of a
20 claim;

21 “(B) is limited to information that is di-
22 rectly related to and necessary for the payment
23 of such claim and the claim would otherwise be
24 denied but for the protected genetic informa-
25 tion; and

1 “(C) is used only by an individual (or indi-
2 viduals) within such issuer who needs access to
3 such information for purposes of payment of a
4 claim.

5 “(6) RULES OF CONSTRUCTION.—

6 “(A) COLLECTION OR DISCLOSURE AU-
7 THORIZED BY INDIVIDUAL.—The provisions of
8 paragraphs (2) (regarding collection) and (3)
9 shall not apply to an individual if the individual
10 (or legal representative of the individual) pro-
11 vides prior, knowing, voluntary, and written au-
12 thorization for the collection or disclosure of
13 protected genetic information.

14 “(B) DISCLOSURE FOR HEALTH CARE
15 TREATMENT.—Nothing in this section shall be
16 construed to limit or restrict the disclosure of
17 protected genetic information from a health
18 care provider to another health care provider
19 for the purpose of providing health care treat-
20 ment to the individual involved.

21 “(7) VIOLATION OF GENETIC DISCRIMINATION
22 OR GENETIC DISCLOSURE PROVISIONS.—

23 “(A) IN GENERAL.—In any action under
24 this subsection against any administrator of a
25 medicare supplemental policy (including any

1 third party administrator or other person acting
2 for or on behalf of such policy) alleging a viola-
3 tion of this subsection, the court may award
4 any appropriate legal or equitable relief. Such
5 relief may include a requirement for the pay-
6 ment of attorney’s fees and costs, including the
7 costs of expert witnesses.

8 “(B) CIVIL PENALTY.—In any action de-
9 scribed in subparagraph (A), the Secretary
10 may, to vindicate the public interest, assess a
11 civil penalty against the defendant in an
12 amount—

13 “(i) not exceeding \$50,000 for a first
14 violation, and

15 “(ii) not exceeding \$100,000 for any
16 subsequent violation.

17 Any such relief awarded shall be paid into the
18 general fund of the Treasury.”.

19 “(8) SPECIAL RULE IN CASE OF GENETIC IN-
20 FORMATION.—This subsection (relating to genetic
21 information or information about a request for, or
22 the receipt of, genetic services by an individual or a
23 family member of such individual) shall not be con-
24 strued to supersede any provision of State law which
25 establishes, implements, or continues in effect a

1 standard, requirement, or remedy that more com-
2 pletely—

3 “(A) protects the confidentiality of genetic
4 information (including information about a re-
5 quest for, or the receipt of, genetic services by
6 an individual or a family member of such indi-
7 vidual) or the privacy of an individual or a fam-
8 ily member of the individual with respect to ge-
9 netic information (including information about
10 a request for, or the receipt of, genetic services
11 by an individual or a family member of such in-
12 dividual) than does this subsection; or

13 “(B) prohibits discrimination on the basis
14 of genetic information than does this sub-
15 section.

16 “(9) DEFINITIONS.—In this subsection:

17 “(A) CONTROLLED GROUP.—The term
18 ‘controlled group’ means any group treated as
19 a single employer under subsection (b), (c),
20 (m), or (o) of section 414 of the Internal Rev-
21 enue Code of 1986.

22 “(B) FAMILY MEMBER.—The term ‘family
23 member’ means with respect to an individual—

24 “(i) the spouse of the individual;

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

4 “(iii) any other individuals related by
5 blood to the individual or to the spouse or
6 child described in clause (i) or (ii).

7 “(C) GENETIC INFORMATION.—The term
8 ‘genetic information’ means information about
9 genes, gene products, or inherited characteris-
10 tics that may derive from an individual or a
11 family member of such individual (including in-
12 formation about a request for, or the receipt of,
13 genetic services by such individual or family
14 member of such individual).

15 “(D) GENETIC SERVICES.—The term ‘ge-
16 netic services’ means health services, including
17 genetic tests, provided to obtain, assess, or in-
18 terpret genetic information for diagnostic and
19 therapeutic purposes, and for genetic education
20 and counseling.

21 “(E) GENETIC TEST.—The term ‘genetic
22 test’ means the analysis of human DNA, RNA,
23 chromosomes, proteins, or metabolites that de-
24 tects genotypes, mutations, or chromosomal
25 changes.

1 “(F) ISSUER OF A MEDICARE SUPPLE-
2 MENTAL POLICY.—The term ‘issuer of a medi-
3 care supplemental policy’ includes a third-party
4 administrator or other person acting for or on
5 behalf of such issuer.

6 “(G) PROTECTED GENETIC INFORMA-
7 TION.—

8 “(i) IN GENERAL.—Except as pro-
9 vided in clause (ii), the term ‘protected ge-
10 netic information’ means—

11 “(I) information about an indi-
12 vidual’s genetic tests;

13 “(II) information about genetic
14 tests of family members of the indi-
15 vidual; and

16 “(III) information about the oc-
17 currence of a disease or disorder in
18 family members.”.

19 “(ii) LIMITATIONS.—The term ‘pro-
20 tected genetic information’ shall not in-
21 clude—

22 “(I) information about the sex or
23 age of the individual;

24 “(II) information about chemical,
25 blood, or urine analyses of the indi-

1 vidual, unless these analyses are ge-
2 netic tests; or

3 “(III) information about physical
4 exams of the individual, and other in-
5 formation that indicates the current
6 health status of the individual.”.

7 (2) CONFORMING AMENDMENT.—Section
8 1882(o) of the Social Security Act (42 U.S.C.
9 1395ss(o)) is amended by adding at the end the fol-
10 lowing:

11 “(4) The issuer of the medicare supplemental
12 policy complies with subsection (s)(2)(E) and sub-
13 section (v).”.

14 (3) EFFECTIVE DATE.—The amendments made
15 by this subsection shall apply with respect to an
16 issuer of a medicare supplemental policy for policy
17 years beginning after October 1, 2005.

18 (c) TRANSITION PROVISIONS.—

19 (1) IN GENERAL.—If the Secretary of Health
20 and Human Services identifies a State as requiring
21 a change to its statutes or regulations to conform its
22 regulatory program to the changes made by this sec-
23 tion, the State regulatory program shall not be con-
24 sidered to be out of compliance with the require-
25 ments of section 1882 of the Social Security Act due

1 solely to failure to make such change until the date
2 specified in paragraph (4).

3 (2) NAIC STANDARDS.—If, not later than June
4 30, 2005, the National Association of Insurance
5 Commissioners (in this subsection referred to as the
6 “NAIC”) modifies its NAIC Model Regulation relat-
7 ing to section 1882 of the Social Security Act (re-
8 ferred to in such section as the 1991 NAIC Model
9 Regulation, as subsequently modified) to conform to
10 the amendments made by this section, such revised
11 regulation incorporating the modifications shall be
12 considered to be the applicable NAIC model regula-
13 tion (including the revised NAIC model regulation
14 and the 1991 NAIC Model Regulation) for the pur-
15 poses of such section.

16 (3) SECRETARY STANDARDS.—If the NAIC
17 does not make the modifications described in para-
18 graph (2) within the period specified in such para-
19 graph, the Secretary of Health and Human Services
20 shall, not later than October 1, 2005, make the
21 modifications described in such paragraph and such
22 revised regulation incorporating the modifications
23 shall be considered to be the appropriate regulation
24 for the purposes of such section.

25 (4) DATE SPECIFIED.—

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

4 (i) the date the State changes its stat-
5 utes or regulations to conform its regu-
6 latory program to the changes made by
7 this section, or

8 (ii) October 1, 2005.

9 (B) ADDITIONAL LEGISLATIVE ACTION RE-
10 QUIRED.—In the case of a State which the Sec-
11 retary identifies as—

12 (i) requiring State legislation (other
13 than legislation appropriating funds) to
14 conform its regulatory program to the
15 changes made in this section, but

16 (ii) having a legislature which is not
17 scheduled to meet in 2005 in a legislative
18 session in which such legislation may be
19 considered,

20 the date specified in this paragraph is the first
21 day of the first calendar quarter beginning after
22 the close of the first legislative session of the
23 State legislature that begins on or after July 1,
24 2005. For purposes of the previous sentence, in
25 the case of a State that has a 2-year legislative

1 session, each year of such session shall be
2 deemed to be a separate regular session of the
3 State legislature.

4 **TITLE II—PROHIBITION OF EM-**
5 **PLOYMENT DISCRIMINATION**
6 **ON THE BASIS OF PRO-**
7 **TECTED GENETIC INFORMA-**
8 **TION**

9 **SEC. 201. DEFINITIONS.**

10 In this title:

11 (1) EMPLOYEE; EMPLOYER; EMPLOYMENT
12 AGENCY; LABOR ORGANIZATION; MEMBER.—The
13 terms “employee”, “employer”, “employment agen-
14 cy”, and “labor organization” have the meanings
15 given such terms in section 701 of the Civil Rights
16 Act of 1964 (42 U.S.C. 2000e), except that the
17 terms “employee” and “employer” shall also include
18 the meanings given such terms in section 717 of the
19 Civil Rights Act of 1964 (42 U.S.C. 2000e–16). The
20 terms “employee” and “member” include an appli-
21 cant for employment and an applicant for member-
22 ship in a labor organization, respectively.

23 (2) FAMILY MEMBER.—The term “family mem-
24 ber” means with respect to an individual—

25 (A) the spouse of the individual;

1 (B) a dependent child of the individual, in-
2 cluding a child who is born to or placed for
3 adoption with the individual; or

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

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

17 (4) GENETIC SERVICES.—The term “genetic
18 services” means health services, including genetic
19 tests, provided to obtain, assess, or interpret genetic
20 information for diagnostic and therapeutic purposes,
21 and for genetic education and counseling.

22 (5) GENETIC TEST.—The term “genetic test”
23 means the analysis of human DNA, RNA, chro-
24 mosomes, proteins, or metabolites that detects
25 genotypes, mutations, or chromosomal changes.

1 (6) PROTECTED GENETIC INFORMATION.—

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

5 (i) information about an individual’s
6 genetic tests;

7 (ii) information about genetic tests of
8 family members of the individual; and

9 (iii) information about the occurrence
10 of a disease or disorder in family members.

11 (B) LIMITATIONS.—The term “protected
12 genetic information” shall not include—

13 (i) information about the sex or age of
14 the individual;

15 (ii) information about chemical, blood,
16 or urine analyses of the individual, unless
17 these analyses are genetic tests; or

18 (iii) information about physical exams
19 of the individual, and other information
20 that indicates the current health status of
21 the individual.

22 **SEC. 202. EMPLOYER PRACTICES.**

23 (a) IN GENERAL.—It shall be an unlawful employ-
24 ment practice for an employer (or a worker’s compensa-
25 tion insurance issuer acting on the employer’s behalf)—

1 (1) to fail or refuse to hire or to discharge any
2 individual, or otherwise to discriminate against any
3 individual with respect to the compensation, terms,
4 conditions, or privileges of employment of the indi-
5 vidual, because of protected genetic information with
6 respect to the individual or information about a re-
7 quest for or the receipt of genetic services by such
8 individual or family member of such individual;

9 (2) to limit, segregate, or classify the employees
10 of the employer in any way that would deprive or
11 tend to deprive any individual of employment oppor-
12 tunities or otherwise adversely affect the status of
13 the individual as an employee, because of protected
14 genetic information with respect to the individual, or
15 information about a request for or the receipt of ge-
16 netic services by such individual or family member
17 of such individual; or

18 (3) to request, require, collect or purchase pro-
19 tected genetic information with respect to an indi-
20 vidual or a family member of the individual except—

21 (A) where used for genetic monitoring of
22 biological effects of toxic substances in the
23 workplace, but only if—

1 (i) the employee has provided prior,
2 knowing, voluntary, and written authoriza-
3 tion;

4 (ii) the employee is informed of indi-
5 vidual monitoring results;

6 (iii) the monitoring conforms to any
7 genetic monitoring regulations that may be
8 promulgated by the Secretary of Labor
9 pursuant to the Occupational Safety and
10 Health Act of 1970 (29 U.S.C. 651 et
11 seq.) or the Federal Mine Safety and
12 Health Act of 1977 (30 U.S.C. 801 et
13 seq.); and

14 (iv) the employer, excluding any li-
15 censed health care professional that is in-
16 volved in the genetic monitoring program,
17 receives the results of the monitoring only
18 in aggregate terms that do not disclose the
19 identity of specific employees;

20 (B) where health or genetic services are of-
21 fered by the employer and the employee pro-
22 vides prior, knowing, voluntary, and written au-
23 thorization, and only the employee or family
24 member of such employee receives the results of
25 such services; or

1 (C) with respect to an applicant who has
2 been given a conditional offer of employment or
3 to an employee, an employer may request, re-
4 quire, collect or purchase the information de-
5 scribed in section 201(6)(C), if—

6 (i) the request or requirement is con-
7 sistent with the Americans with Disabil-
8 ities Act of 1990 (42 U.S.C. 12101 et
9 seq.) or the Rehabilitation Act of 1973 (29
10 U.S.C. 701 et seq.); and

11 (ii)(I) the information obtained is to
12 be used exclusively to assess whether fur-
13 ther medical evaluation is needed to diag-
14 nose a current disease, or medical condi-
15 tion or disorder;

16 (II) such current disease, or medical
17 condition or disorder could prevent the ap-
18 plicant or employee from performing the
19 essential functions of the position desired
20 or held; and

21 (III) the information described in
22 such section will not be disclosed to per-
23 sons other than medical personnel involved
24 in or responsible for assessing whether fur-
25 ther medical evaluation is needed to diag-

1 nose a current disease, or medical condi-
2 tion or disorder, except as otherwise per-
3 mitted by this title.

4 (b) LIMITATION.—In the case of protected genetic in-
5 formation to which subparagraph (A), (B), or (C) of sub-
6 section (a)(3) applies, such information may not be used
7 in violation of paragraph (1) or (2) of subsection (a).

8 **SEC. 203. EMPLOYMENT AGENCY PRACTICES.**

9 It shall be an unlawful employment practice for an
10 employment agency—

11 (1) to fail or refuse to refer for employment, or
12 otherwise to discriminate against, any individual be-
13 cause of protected genetic information with respect
14 to the individual (or information about a request for
15 or the receipt of genetic services by such individual
16 or family member of such individual);

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

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

3 (3) to request, require, collect or purchase pro-
4 tected genetic information with respect to an indi-
5 vidual (or information about a request for or the re-
6 ceipt of genetic services by such individual or family
7 member of such individual); or

8 (4) to cause or attempt to cause an employer to
9 discriminate against an individual in violation of this
10 title.

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

12 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 individual because of protected genetic
17 information with respect to the individual (or infor-
18 mation about a request for or the receipt of genetic
19 services by such individual or family member of such
20 individual);

21 (2) to limit, segregate, or classify the members
22 of the organization, or fail or refuse to refer for em-
23 ployment any individual, in any way that would de-
24 prive or tend to deprive any individual of employ-
25 ment opportunities, or would limit the employment

1 opportunities or otherwise adversely affect the status
2 of the individual as an employee, because of pro-
3 tected genetic information with respect to the indi-
4 vidual (or information about a request for or the re-
5 ceipt of genetic services by such individual or family
6 member of such individual);

7 (3) to request, require, collect or purchase pro-
8 tected genetic information with respect to an indi-
9 vidual (or information about a request for or the re-
10 ceipt of genetic services by such individual or family
11 member of such individual); or

12 (4) to cause or attempt to cause an employer to
13 discriminate against an individual in violation of this
14 title.

15 **SEC. 205. TRAINING PROGRAMS.**

16 It shall be an unlawful employment practice for any
17 employer, labor organization, or joint labor-management
18 committee controlling apprenticeship or other training or
19 retraining, including on-the-job training programs—

20 (1) to discriminate against any individual be-
21 cause of protected genetic information with respect
22 to the individual (or information about a request for
23 or the receipt of genetic services by such individual),
24 in admission to, or employment in, any program es-

1 established to provide apprenticeship or other training
2 or retraining;

3 (2) to limit, segregate, or classify the members
4 of the organization, or fail or refuse to refer for em-
5 ployment any individual, in any way that would de-
6 prive or tend to deprive any individual of employ-
7 ment opportunities, or would limit the employment
8 opportunities or otherwise adversely affect the status
9 of the individual as an employee, because of pro-
10 tected genetic information with respect to the indi-
11 vidual (or information about a request for or receipt
12 of genetic services by such individual or family mem-
13 ber of such individual);

14 (3) to request, require, collect or purchase pro-
15 tected genetic information with respect to an indi-
16 vidual (or information about a request for or receipt
17 of genetic services by such individual or family mem-
18 ber of such individual); or

19 (4) to cause or attempt to cause an employer to
20 discriminate against an individual in violation of this
21 title.

22 **SEC. 206. MAINTENANCE AND DISCLOSURE OF PROTECTED**
23 **GENETIC INFORMATION.**

24 (a) MAINTENANCE OF PROTECTED GENETIC INFOR-
25 MATION.—If an employer (or a worker’s compensation in-

1 surance issuer acting on the employer's behalf) possesses
2 protected genetic information about an employee (or infor-
3 mation about a request for or receipt of genetic services
4 by such employee or family member of such employee),
5 such information shall be treated and maintained as part
6 of the employee's confidential medical records.

7 (b) DISCLOSURE OF PROTECTED GENETIC INFORMA-
8 TION.—An employer (or a worker's compensation insur-
9 ance issuer acting on the employer's behalf) shall not dis-
10 close protected genetic information (or information about
11 a request for or receipt of genetic services by such em-
12 ployee or family member of such employee) except—

13 (1) to the employee who is the subject of the in-
14 formation at the request of the employee;

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

20 (3) under legal compulsion of a Federal court
21 order, except that if the court order was secured
22 without the knowledge of the individual to whom the
23 information refers, the employer (or a worker's com-
24 pensation insurance issuer acting on the employer's
25 behalf) shall provide the individual with adequate

1 notice to challenge the court order unless the court
2 order also imposes confidentiality requirements; and
3 (4) to government officials who are inves-
4 tigating compliance with this title if the information
5 is relevant to the investigation.

6 **SEC. 207. CIVIL ACTION.**

7 (a) IN GENERAL.—One or more employees, members
8 of a labor organization, or participants in training pro-
9 grams or a labor organization may bring an action in a
10 Federal or State court of competent jurisdiction against
11 an employer (or a worker’s compensation insurance issuer
12 acting on the employer’s behalf), employment agency,
13 labor organization, or joint labor-management committee
14 or training program who commits a violation of this title.

15 (b) ENFORCEMENT BY THE EQUAL EMPLOYMENT
16 OPPORTUNITY COMMISSION.—

17 (1) IN GENERAL.—The powers, remedies, and
18 procedures set forth in sections 705, 706, 707, 709,
19 710, and 717 of the Civil Rights Act of 1964 (42
20 U.S.C. 2000e–4, 2000e–5, 2000e–6, 2000e–8,
21 2000e–9, and 2000e–16) shall be the powers, rem-
22 edies, and procedures provided to the Equal Employ-
23 ment Opportunity Commission to enforce this title.
24 The Commission may promulgate regulations to im-
25 plement these powers, remedies, and procedures.

1 (2) EXHAUSTION OF REMEDIES.—Nothing in
2 this subsection shall be construed to require that an
3 individual exhaust the administrative remedies avail-
4 able through the Equal Employment Opportunity
5 Commission prior to commencing a civil action
6 under this section, except that if an individual files
7 a charge of discrimination with the Commission that
8 alleges a violation of this title, the individual shall
9 exhaust the administrative remedies available
10 through the Commission prior to commencing a civil
11 action under this section.

12 (c) REMEDY.—A Federal or State court may award
13 any appropriate legal or equitable relief under this section.
14 Such relief may include a requirement for the payment
15 of attorney’s fees and costs, including the cost of experts.

16 **SEC. 208. EXCEPTIONS; RULES OF CONSTRUCTION.**

17 (a) TREATMENT OF CERTAIN TESTS.—The con-
18 ducting of metabolic tests that are not intended to reveal
19 protected genetic information shall not be considered a
20 violation of 203(a)(3), 204(3), 205(3), or 206(3) regard-
21 less of the results of the tests. Test results that are pro-
22 tected genetic information shall be subject to the applica-
23 ble provisions of this title.

24 (b) RULES OF CONSTRUCTION.—Nothing in this title
25 shall be construed to—

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

6 (2) limit the rights or protections of an indi-
7 vidual under the Rehabilitation Act of 1973 (29
8 U.S.C. 701 et seq.);

9 (3) limit the rights or protections of an indi-
10 vidual under any other Federal or State statute that
11 provides equal or greater protection to an individual
12 than the rights accorded under this title;

13 (4) apply to the Armed Forces Repository of
14 Specimen Samples for the Identification of Remains;
15 or

16 (5) limit the statutory or regulatory authority
17 of the Occupational Safety and Health Administra-
18 tion or the Mine Safety and Health Administration
19 to promulgate or enforce workplace safety and
20 health laws and regulations.

21 **SEC. 209. AUTHORIZATION OF APPROPRIATIONS.**

22 There are authorized to be appropriated such sums
23 as may be necessary to carry out this title.

24 **SEC. 210. EFFECTIVE DATE.**

25 This title shall become effective on October 1, 2005.

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

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