

107TH CONGRESS
1ST SESSION

S. 318

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

IN THE SENATE OF THE UNITED STATES

FEBRUARY 13, 2001

Mr. DASCHLE (for himself, Mr. HARKIN, Mr. DODD, Mr. KENNEDY, Mr. BIDEN, Mr. BINGAMAN, Mrs. CLINTON, Mr. DURBIN, Mr. INOUE, Mr. KERRY, Mr. LEAHY, Ms. MIKULSKI, Mrs. MURRAY, Mr. ROCKEFELLER, Mr. SARBANES, Mr. SCHUMER, and Mr. CORZINE) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

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

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

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Genetic Non-
5 discrimination in Health Insurance and Employment
6 Act”.

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

12 “(e) DISCLOSURE OF PROTECTED GENETIC INFOR-
13 MATION.—A group health plan, or a health insurance
14 issuer offering health insurance coverage in connection
15 with a group health plan, shall not disclose protected ge-
16 netic information about an individual (or information
17 about a request for or the receipt of genetic services by
18 such individual or family member of such individual) to—

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

22 “(2) any other group health plan or health in-
23 surance issuer or any insurance agent, third party
24 administrator, or other person subject to regulation
25 under State insurance laws;

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

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

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

8 “(f) INFORMATION FOR PAYMENT FOR GENETIC
9 SERVICES.—

10 “(1) IN GENERAL.—With respect to payment
11 for genetic services conducted concerning an indi-
12 vidual or the coordination of benefits, a group health
13 plan, or a health insurance issuer offering group
14 health insurance coverage in connection with a group
15 health plan, may request that the individual provide
16 the plan or issuer with evidence that such services
17 were performed.

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

20 “(A) permit a group health plan or health
21 insurance issuer to request (or require) the re-
22 sults of the services referred to in such para-
23 graph; or

24 “(B) require that a group health plan or
25 health insurance issuer make payment for serv-

1 ices described in such paragraph where the in-
2 dividual involved has refused to provide evi-
3 dence of the performance of such services pur-
4 suant to a request by the plan or issuer in ac-
5 cordance with such paragraph.

6 “(g) INFORMATION FOR PAYMENT OF OTHER
7 CLAIMS.—With respect to the payment of claims for bene-
8 fits other than genetic services, a group health plan, or
9 a health insurance issuer offering group health insurance
10 coverage in connection with a group health plan, may re-
11 quest that an individual provide protected genetic informa-
12 tion so long as such information—

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

14 “(2) is limited to information that is directly re-
15 lated to and necessary for the payment of such claim
16 and the claim would otherwise be denied but for the
17 protected genetic information; and

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

22 “(h) RULES OF CONSTRUCTION.—

23 “(1) COLLECTION OR DISCLOSURE AUTHORIZED
24 BY INDIVIDUAL.—The provisions of subsections (d)
25 (regarding collection) and (e) shall not apply to an

1 individual if the individual (or legal representative of
2 the individual) provides prior, knowing, voluntary,
3 and written authorization for the collection or disclo-
4 sure of protected genetic information.

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

11 “(i) DEFINITIONS.—In this section:

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

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

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

23 “(n) VIOLATION OF GENETIC DISCRIMINATION OR
24 GENETIC DISCLOSURE PROVISIONS.—In any action under
25 this section against any administrator of a group health

1 plan, or health insurance issuer offering group health in-
2 surance coverage in connection with a group health plan
3 (including any third party administrator or other person
4 acting for or on behalf of such plan or issuer) alleging
5 a violation of subsection (a)(1)(F), (b) (with respect to
6 cases relating to genetic information or information about
7 a request or receipt of genetic services by an individual
8 or family member of such individual), (c), (d), (e), (f), or
9 (g) of section 702, or section 714, the court may award
10 any appropriate legal or equitable relief. Such relief may
11 include a requirement for the payment of attorney’s fees
12 and costs, including the costs of expert witnesses.

13 “(o) CIVIL PENALTY.—The monetary provisions of
14 section 308(b)(2)(C) of Public Law 101–336 (42 U.S.C.
15 12188(b)(2)(C)) shall apply for purposes of the Secretary
16 enforcing the provisions referred to in subsection (n), ex-
17 cept that any such relief awarded shall be paid only into
18 the general fund of the Treasury.”.

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

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

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

1 “(e) SPECIAL RULE IN CASE OF GENETIC INFORMA-
2 TION.—With respect to group health insurance coverage
3 offered by a health insurance issuer, the provisions of this
4 part relating to genetic information (including information
5 about a request for or the receipt of genetic services by
6 an individual or a family member of such individual) shall
7 not be construed to supersede any provision of State law
8 which establishes, implements, or continues in effect a
9 standard, requirement, or remedy that more completely—

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

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

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

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

1 “(A) the spouse of the individual;

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

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

8 “(6) GENETIC INFORMATION.—The term ‘ge-
9 netic information’ means information about genes,
10 gene products, or inherited characteristics that may
11 derive from an individual or a family member of
12 such individual (including information about a re-
13 quest for or the receipt of genetic services by such
14 individual or family member of such individual).

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

20 “(8) GENETIC TEST.—(A) IN GENERAL.—The
21 term ‘genetic test’ means the analysis of human
22 DNA, RNA, chromosomes, proteins, or metabolites
23 that detect genotypes, mutations, or chromosomal
24 changes.

1 “(B) CERTAIN TESTS.—Notwithstanding sub-
2 paragraph (A), the conducting of metabolic tests
3 that are not intended to reveal protected genetic in-
4 formation shall not be considered a violation of sec-
5 tion 702(c) for purposes of such subparagraph re-
6 gardless of the results of the tests. Test results that
7 are protected genetic information shall be subject to
8 the applicable provisions of this part.

9 “(9) PROTECTED GENETIC INFORMATION.—The
10 term ‘protected genetic information’ means—

11 “(A) information about an individual’s ge-
12 netic tests;

13 “(B) information about genetic tests of
14 family members of the individual; or

15 “(C) information about the occurrence of a
16 disease or disorder in family members.

17 (f) LIMITATIONS WITH RESPECT TO DEFINITION.—
18 Section 702 of the Employee Retirement Income Security
19 Act of 1974 (29 U.S.C. 1182), as amended by subsection
20 (b), is further amended by adding at the end the following:

21 “(j) LIMITATIONS.—As defined in section 933(d)(9),
22 the term protected genetic information shall not include—

23 “(1) information about the sex or age of the in-
24 dividual;

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

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

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

17 (h) EFFECTIVE DATE.—

18 (1) IN GENERAL.—Except as provided in this
19 section, this section and the amendments made by
20 this section shall apply with respect to group health
21 plans for plan years beginning after October 1,
22 2002.

23 (2) SPECIAL RULE FOR COLLECTIVE BAR-
24 GAINING AGREEMENTS.—In the case of a group
25 health plan maintained pursuant to one or more col-

1 lective bargaining agreements between employee rep-
 2 resentatives and one or more employers ratified be-
 3 fore the date of the enactment of this Act, this sec-
 4 tion and the amendments made by this section shall
 5 not apply to plan years beginning before the later
 6 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, 2002.

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. 102. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**

21 **ACT.**

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

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

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

12 (B) NO DISCRIMINATION IN GROUP RATE
 13 BASED ON PROTECTED GENETIC INFORMA-
 14 TION.—

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

20 **“SEC. 2707. PROHIBITING DISCRIMINATION AGAINST**
 21 **GROUPS ON THE BASIS OF PROTECTED GE-**
 22 **NETIC INFORMATION.**

23 “A group health plan, and a health insurance issuer
 24 offering group health insurance coverage in connection
 25 with a group health plan, shall not deny eligibility to a

1 group or adjust premium or contribution rates for a group
2 on the basis of protected genetic information concerning
3 an individual in the group (or information about a request
4 for or the receipt of genetic services by such individual
5 or family member of such individual).”.

6 (ii) CONFORMING AMENDMENTS.—

7 (I) Section 2702(b)(2)(A) of the
8 Public Health Service Act (42 U.S.C.
9 300gg-1(b)(2)(A)) is amended to read
10 as follows:

11 “(A) to restrict the amount that an em-
12 ployer may be charged for coverage under a
13 group health plan, except as provided in section
14 2707; or”.

15 (II) Section 2721(a) of the Pub-
16 lic Health Service Act (42 U.S.C.
17 300gg-21(a)) is amended by inserting
18 “(other than subsections (a)(1)(F),
19 (b) (with respect to cases relating to
20 genetic information or information
21 about a request or receipt of genetic
22 services by an individual or family
23 member of such individual), (c), (d),
24 (e), (f), or (g) of section 2702 and

1 section 2707)” after “subparts 1 and
2 3”.

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

8 “(c) GENETIC TESTING.—

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

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

1 “(d) COLLECTION OF PROTECTED GENETIC INFOR-
2 MATION.—Except as provided in subsections (f) and (g),
3 a group health plan, or a health insurance issuer offering
4 health insurance coverage in connection with a group
5 health plan, shall not request, require, collect, or purchase
6 protected genetic information concerning an individual (or
7 information about a request for or the receipt of genetic
8 services by such individual or family member of such indi-
9 vidual).

10 “(e) DISCLOSURE OF PROTECTED GENETIC INFOR-
11 MATION.—A group health plan, or a health insurance
12 issuer offering health insurance coverage in connection
13 with a group health plan, shall not disclose protected ge-
14 netic information about an individual (or information
15 about a request for or the receipt of genetic services by
16 such individual or family member of such individual) to—

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

20 “(2) any other group health plan or health in-
21 surance issuer or any insurance agent, third party
22 administrator, or other person subject to regulation
23 under State insurance laws;

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

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

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

8 “(f) INFORMATION FOR PAYMENT FOR GENETIC
9 SERVICES.—

10 “(1) IN GENERAL.—With respect to payment
11 for genetic services conducted concerning an indi-
12 vidual or the coordination of benefits, a group health
13 plan, or a health insurance issuer offering group
14 health insurance coverage in connection with a group
15 health plan, may request that the individual provide
16 the plan or issuer with evidence that such services
17 were performed.

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

20 “(A) permit a group health plan or health
21 insurance issuer to request (or require) the re-
22 sults of the services referred to in such para-
23 graph; or

24 “(B) require that a group health plan or
25 health insurance issuer make payment for serv-

1 ices described in such paragraph where the in-
2 dividual involved has refused to provide evi-
3 dence of the performance of such services pur-
4 suant to a request by the plan or issuer in ac-
5 cordance with such paragraph.

6 “(g) INFORMATION FOR PAYMENT OF OTHER
7 CLAIMS.—With respect to the payment of claims for bene-
8 fits other than genetic services, a group health plan, or
9 a health insurance issuer offering group health insurance
10 coverage in connection with a group health plan, may re-
11 quest that an individual provide protected genetic informa-
12 tion so long as such information—

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

14 “(2) is limited to information that is directly re-
15 lated to and necessary for the payment of such claim
16 and the claim would otherwise be denied but for the
17 protected genetic information; and

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

22 “(h) RULES OF CONSTRUCTION.—

23 “(1) COLLECTION OR DISCLOSURE AUTHORIZED
24 BY INDIVIDUAL.—The provisions of subsections (d)
25 (regarding collection) and (e) shall not apply to an

1 individual if the individual (or legal representative of
2 the individual) provides prior, knowing, voluntary,
3 and written authorization for the collection or disclo-
4 sure of protected genetic information.

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

11 “(i) DEFINITIONS.—In this section:

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

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

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

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

3 “(A) the spouse of the individual;

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

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

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

17 “(17) 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 counselling.

22 “(18) GENETIC TEST.—

23 “(A) IN GENERAL.—The term ‘genetic
24 test’ means the analysis of human DNA, RNA,
25 chromosomes, proteins, or metabolites that de-

1 tect genotypes, mutations, or chromosomal
2 changes.

3 “(B) CERTAIN TESTS.—Notwithstanding
4 subparagraph (A), the conducting of metabolic
5 tests that are not intended to reveal protected
6 genetic information shall not be considered a
7 violation of section 2702(c) or 2754(a) for pur-
8 poses of such subparagraph regardless of the
9 results of the tests. Test results that are pro-
10 tected genetic information shall be subject to
11 the applicable provisions of this title.

12 “(19) PROTECTED GENETIC INFORMATION.—
13 The term ‘protected genetic information’ means—

14 “(A) information about an individual’s ge-
15 netic tests;

16 “(B) information about genetic tests of
17 family members of the individual; or

18 “(C) information about the occurrence of a
19 disease or disorder in family members.”.

20 (4) LIMITATIONS WITH RESPECT TO DEFINI-
21 TION.—Section 2702 of the Public Health Service
22 Act (42 U.S.C. 300gg–1), as amended by paragraph
23 (2), is further amended by adding at the end the fol-
24 lowing:

1 “(j) LIMITATIONS.—As defined in section
2 2791(d)(19), the term protected genetic information shall
3 not include—

4 “(1) information about the sex or age of the in-
5 dividual;

6 “(2) information about chemical, blood, or urine
7 analyses of the individual, unless these analyses are
8 genetic tests; or

9 “(3) information about physical exams of the
10 individual, and other information that indicates the
11 current health status of the individual.”.

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

16 (1) by redesignating such subpart as subpart 2;
17 and

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

19 **“SEC. 2753. PROHIBITION OF HEALTH INSURANCE DIS-**
20 **CRIMINATION AGAINST INDIVIDUALS ON THE**
21 **BASIS OF PROTECTED GENETIC INFORMA-**
22 **TION.**

23 “(a) INELIGIBILITY TO ENROLL.—A health insur-
24 ance issuer offering health insurance coverage in the indi-
25 vidual market shall not establish rules for eligibility to en-

1 roll in individual health insurance coverage that are based
2 on protected genetic information concerning the individual
3 (or information about a request for or the receipt of ge-
4 netic services by such individual or family member of such
5 individual).

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

13 **“SEC. 2754. LIMITATIONS ON GENETIC TESTING AND ON**
14 **COLLECTION AND DISCLOSURE OF PRO-**
15 **TECTED GENETIC INFORMATION.**

16 “(a) GENETIC TESTING.—

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

23 “(2) RULE OF CONSTRUCTION.—Nothing in
24 this title shall be construed to limit the authority of
25 a health care professional, who is providing treat-

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

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

16 “(c) DISCLOSURE OF PROTECTED GENETIC INFOR-
17 MATION.—A health insurance issuer offering health insur-
18 ance coverage in the individual market shall not disclose
19 protected genetic information about an individual (or in-
20 formation about a request for or the receipt of genetic
21 services by such individual or family member of such indi-
22 vidual) to—

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

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

5 “(3) the Medical Information Bureau or any
 6 other person that collects, compiles, publishes, or
 7 otherwise disseminates insurance information;

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

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

12 “(d) INFORMATION FOR PAYMENT FOR GENETIC
 13 SERVICES.—

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

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

23 “(A) permit a health insurance issuer to
 24 request (or require) the results of the services
 25 referred to in such paragraph; or

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

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

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

14 “(2) is limited to information that is directly re-
15 lated to and necessary for the payment of such claim
16 and the claim would otherwise be denied but for the
17 protected genetic information; and

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

22 “(f) RULES OF CONSTRUCTION.—

23 “(1) COLLECTION OR DISCLOSURE AUTHORIZED
24 BY INDIVIDUAL.—The provisions of subsections (c)
25 (regarding collection) and (d) shall not apply to an

1 individual if the individual (or legal representative of
2 the individual) provides prior, knowing, voluntary,
3 and written authorization for the collection or disclo-
4 sure of protected genetic information.

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

11 “(g) DEFINITIONS.—In this section:

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

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

21 (c) ENFORCEMENT.—

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

1 “(c) VIOLATION OF GENETIC DISCRIMINATION OR
2 GENETIC DISCLOSURE PROVISIONS.—In any action under
3 this section against any administrator of a group health
4 plan, or health insurance issuer offering group health in-
5 surance coverage in connection with a group health plan
6 (including any third party administrator or other person
7 acting for or on behalf of such plan or issuer) alleging
8 a violation of subsections (a)(1)(F), (b) (with respect to
9 cases relating to genetic information or information about
10 a request or receipt of genetic services by an individual
11 or family member of such individual), (c), (d), (e), (f), or
12 (g) of section 2702 and section 2707 the court may award
13 any appropriate legal or equitable relief. Such relief may
14 include a requirement for the payment of attorney’s fees
15 and costs, including the costs of expert witnesses.

16 “(d) CIVIL PENALTY.—The monetary provisions of
17 section 308(b)(2)(C) of Public Law 101–336 (42 U.S.C.
18 12188(b)(2)(C)) shall apply for purposes of the Secretary
19 enforcing the provisions referred to in subsection (c), ex-
20 cept that any such relief awarded shall be paid only into
21 the general fund of the Treasury.”.

22 (2) INDIVIDUAL PLANS.—Section 2761 of the
23 Public Health Service Act (42 U.S.C. 300gg–45) is
24 amended by adding at the end the following:

1 “(c) VIOLATION OF GENETIC DISCRIMINATION OR
 2 GENETIC DISCLOSURE PROVISIONS.—In any action under
 3 this section against any health insurance issuer offering
 4 health insurance coverage in the individual market (in-
 5 cluding any other person acting for or on behalf of such
 6 issuer) alleging a violation of sections 2753 and 2754 the
 7 court in which the action is commenced may award any
 8 appropriate legal or equitable relief. Such relief may in-
 9 clude a requirement for the payment of attorney’s fees and
 10 costs, including the costs of expert witnesses.

11 “(d) CIVIL PENALTY.—The monetary provisions of
 12 section 308(b)(2)(C) of Public Law 101–336 (42 U.S.C.
 13 12188(b)(2)(C)) shall apply for purposes of the Secretary
 14 enforcing the provisions referred to in subsection (c), ex-
 15 cept that any such relief awarded shall be paid only into
 16 the general fund of the Treasury.”.

17 (d) PREEMPTION.—

18 (1) GROUP MARKET.—Section 2723 of the Pub-
 19 lic Health Service Act (42 U.S.C. 300gg–23) is
 20 amended—

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

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

24 “(e) SPECIAL RULE IN CASE OF GENETIC INFORMA-
 25 TION.—With respect to group health insurance coverage

1 offered by a health insurance issuer, the provisions of this
 2 part relating to genetic information (including information
 3 about a request for or the receipt of genetic services by
 4 an individual or a family member of such individual) shall
 5 not be construed to supersede any provision of State law
 6 which establishes, implements, or continues in effect a
 7 standard, requirement, or remedy that more completely—

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

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

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

22 (A) in subsection (a), by inserting “and ex-
 23 cept as provided in subsection (e),” after “Sub-
 24 ject to subsection (b),”; and

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

1 “(c) SPECIAL RULE IN CASE OF GENETIC INFORMA-
2 TION.—With respect to individual health insurance cov-
3 erage offered by a health insurance issuer, the provisions
4 of this part (or part C insofar as it applies to this part)
5 relating to genetic information (including information
6 about a request for or the receipt of genetic services by
7 an individual or a family member of such individual) shall
8 not be construed to supersede any provision of State law
9 (as defined in section 2723(d)) which establishes, imple-
10 ments, or continues in effect a standard, requirement, or
11 remedy that more completely—

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

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

1 (e) ELIMINATION OF OPTION OF NON-FEDERAL
 2 GOVERNMENTAL PLANS TO BE EXCEPTED FROM RE-
 3 QUIREMENTS CONCERNING GENETIC INFORMATION.—

4 Section 2721(b)(2) of the Public Health Service Act (42
 5 U.S. C. 300gg–21(b)(2)) is amended—

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

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

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

21 (f) AMENDMENT CONCERNING SUPPLEMENTAL EX-
 22 CEPTED BENEFITS.—

23 (1) GROUP MARKET.—Section 2721(d)(3) of
 24 the Public Health Service Act (42 U.S.C. 300gg–
 25 23(d)(3)) is amended by inserting “, other than the

1 requirements of subsections (a)(1)(F), (b) (in cases
2 relating to genetic information or information about
3 a request for or the receipt of genetic services by an
4 individual or a family member of such individual)),
5 (c), (d), (e), (f) and (g) of section 2702 and section
6 2707,” after “The requirements of this part”.

7 (2) INDIVIDUAL MARKET.—Section 2763(b) of
8 the Public Health Service Act (42 U.S.C. 300gg–
9 47(b)) is amended—

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

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

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

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

18 (g) EFFECTIVE DATE.—

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

21 (A) group health plans, and health insur-
22 ance coverage offered in connection with group
23 health plans, for plan years beginning; and

1 (B) health insurance coverage offered,
2 sold, issued, renewed, in effect, or operated in
3 the individual market, after;
4 October 1, 2002.

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

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

18 (B) October 1, 2002.

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

1 **SEC. 103. AMENDMENTS TO INTERNAL REVENUE CODE OF**
 2 **1986.**

3 (a) **PROHIBITION OF HEALTH INSURANCE DISCRIMI-**
 4 **NATION ON THE BASIS OF GENETIC SERVICES OR PRO-**
 5 **TECTED GENETIC INFORMATION.—**

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

12 (2) **NO DISCRIMINATION IN GROUP RATE BASED**
 13 **ON PROTECTED GENETIC INFORMATION.—**

14 (A) **IN GENERAL.—**Subchapter B of chap-
 15 ter 100 of the Internal Revenue Code of 1986
 16 is amended by adding at the end the following:

17 **“SEC. 9813. PROHIBITING DISCRIMINATION AGAINST**
 18 **GROUPS ON THE BASIS OF PROTECTED GE-**
 19 **NETIC INFORMATION.**

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

26 (B) **CONFORMING AMENDMENTS.—**

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

4 “(A) to restrict the amount that an em-
5 ployer may be charged for coverage under a
6 group health plan, except as provided in section
7 9813; or”.

8 (ii) Section 9831(a) of the Internal
9 Revenue Code of 1986 is amended by in-
10 sserting “(other than subsections (a)(1)(F),
11 (b) (with respect to cases relating to ge-
12 netic information or information about a
13 request or receipt of genetic services by an
14 individual or family member of such indi-
15 vidual), (d) (e), (f), (g) or (h) of section
16 9802 or section 9813) after “chapter”.

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

22 “(d) GENETIC TESTING.—

23 “(1) LIMITATION ON REQUESTING OR REQUIR-
24 ING GENETIC TESTING.—A group health plan may

1 not request or require an individual or a family
2 member of such individual to undergo a genetic test.

3 “(2) RULE OF CONSTRUCTION.—Nothing in
4 this chapter shall be construed to limit the authority
5 of a health care professional, who is providing treat-
6 ment with respect to an individual and who is em-
7 ployed by a group health plan, to request that such
8 individual or family member of such individual un-
9 dergo a genetic test. Such a health care professional
10 shall not require that such individual or family mem-
11 ber undergo a genetic test.

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

19 “(f) DISCLOSURE OF PROTECTED GENETIC INFOR-
20 MATION.—A group health plan shall not disclose protected
21 genetic information about an individual (or information
22 about a request for or the receipt of genetic services by
23 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 “(g) 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 may request that the individual provide the
21 plan with evidence that such services were per-
22 formed.

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

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

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

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

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

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

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

24 “(i) RULES OF CONSTRUCTION.—

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

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

14 “(j) DEFINITIONS.—In this section:

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

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

25 “(9) GENETIC TEST.—

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

6 “(B) CERTAIN TESTS.—Notwithstanding
7 subparagraph (A), the conducting of metabolic
8 tests that are not intended to reveal protected
9 genetic information shall not be considered a
10 violation of section 9802(d) for purposes of
11 such subparagraph regardless of the results of
12 the tests. Test results that are protected genetic
13 information shall be subject to the applicable
14 provisions of this chapter.

15 “(10) PROTECTED GENETIC INFORMATION.—
16 The term ‘protected genetic information’ means—

17 “(A) information about an individual’s ge-
18 netic tests;

19 “(B) information about genetic tests of
20 family members of the individual; or

21 “(C) information about the occurrence of a
22 disease or disorder in family members.

23 (d) LIMITATIONS WITH RESPECT TO DEFINITION.—
24 Section 9802 of the Internal Revenue Code of 1986, as

1 amended by subsection (b), is further amended by adding
2 at the end the following:

3 “(k) LIMITATIONS.—As defined in section
4 9832(d)(10), the term protected genetic information shall
5 not include—

6 “(1) information about the sex or age of the in-
7 dividual;

8 “(2) information about chemical, blood, or urine
9 analyses of the individual, unless these analyses are
10 genetic tests; or

11 “(3) information about physical exams of the
12 individual, and other information that indicates the
13 current health status of the individual.”.

14 (e) EFFECTIVE DATE.—

15 (1) IN GENERAL.—Except as provided in this
16 section, this section and the amendments made by
17 this section shall apply with respect to group health
18 plans for plan years beginning after October 1,
19 2002.

20 (2) SPECIAL RULE FOR COLLECTIVE BAR-
21 GAINING AGREEMENTS.—In the case of a group
22 health plan maintained pursuant to one or more col-
23 lective bargaining agreements between employee rep-
24 resentatives and one or more employers ratified be-
25 fore the date of the enactment of this Act, this sec-

1 tion and the amendments made by this section shall
 2 not apply to plan years beginning before the later
 3 of—

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

9 (B) October 1, 2002.

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

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

19 (a) NONDISCRIMINATION.—

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

23 “(E)(i) An issuer of a medicare supple-
 24 mental policy shall not deny or condition the
 25 issuance or effectiveness of the policy, and shall

1 not discriminate in the pricing of the policy (in-
2 cluding the adjustment of premium rates) of an
3 eligible individual on the basis of protected ge-
4 netic information concerning the individual (or
5 information about a request for, or the receipt
6 of, genetic services by such individual or family
7 member of such individual).

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

12 (2) EFFECTIVE DATE.—The amendment made
13 by paragraph (1) shall apply with respect to a policy
14 for policy years beginning after October 1, 2002.

15 (b) LIMITATIONS ON GENETIC TESTING AND ON
16 COLLECTION AND DISCLOSURE OF PROTECTED GENETIC
17 INFORMATION.—

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

21 “(v) LIMITATIONS ON GENETIC TESTING AND ON
22 COLLECTION AND DISCLOSURE OF PROTECTED GENETIC
23 INFORMATION.—

24 “(1) GENETIC TESTING.—

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

6 “(B) RULE OF CONSTRUCTION.—Nothing
7 in this title shall be construed to limit the au-
8 thority of a health care professional, who is pro-
9 viding treatment with respect to an individual
10 and who is employed by an issuer of a medicare
11 supplemental policy, to request that such indi-
12 vidual or family member of such individual un-
13 dergo a genetic test. Such a health care profes-
14 sional shall not require that such individual or
15 family member undergo a genetic test.

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

24 “(3) DISCLOSURE OF PROTECTED GENETIC IN-
25 FORMATION.—An issuer of a medicare supplemental

1 policy shall not disclose protected genetic informa-
 2 tion about an individual (or information about a re-
 3 quest for or the receipt of genetic services by such
 4 individual or family member of such individual) to—

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

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

12 “(C) the Medical Information Bureau or
 13 any other person that collects, compiles, pub-
 14 lishes, or otherwise disseminates insurance in-
 15 formation;

16 “(D) the individual’s employer or any plan
 17 sponsor; or

18 “(E) any other person the Secretary may
 19 specify in regulations.

20 “(4) INFORMATION FOR PAYMENT FOR GE-
 21 NETIC SERVICES.—

22 “(A) IN GENERAL.—With respect to pay-
 23 ment for genetic services conducted concerning
 24 an individual or the coordination of benefits, an
 25 issuer of a medicare supplemental policy may

1 request that the individual provide the issuer
2 with evidence that such services were per-
3 formed.

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

6 “(i) permit an issuer to request (or
7 require) the results of the services referred
8 to in such subparagraph; or

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

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

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

24 “(B) is limited to information that is di-
25 rectly related to and necessary for the payment

1 of such claim and the claim would otherwise be
2 denied but for the protected genetic informa-
3 tion; and

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

8 “(6) RULES OF CONSTRUCTION.—

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

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

24 “(7) VIOLATION OF GENETIC DISCRIMINATION
25 OR GENETIC DISCLOSURE PROVISIONS.—In any ac-

1 tion under this subsection against any administrator
2 of a medicare supplemental policy (including any
3 third party administrator or other person acting for
4 or on behalf of such policy) alleging a violation of
5 this subsection, the court may award any appro-
6 priate legal or equitable relief. Such relief may in-
7 clude a requirement for the payment of attorney’s
8 fees and costs, including the costs of expert wit-
9 nesses.

10 “(8) CIVIL PENALTY.—The monetary provisions
11 of section 308(b)(2)(C) of Public Law 101–336 (42
12 U.S.C. 12188(b)(2)(C)) shall apply for purposes of
13 the Secretary enforcing the provisions of this sub-
14 section, except that any such relief awarded shall be
15 paid only into the general fund of the Treasury.

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

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

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

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

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

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

22 “(i) the spouse of the individual;

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

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

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

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

18 “(E) GENETIC TEST.—

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

24 “(ii) CERTAIN TESTS.—Notwith-
25 standing subparagraph (A), the conducting

1 of metabolic tests that are not intended to
2 reveal protected genetic information shall
3 not be considered a violation of paragraph
4 (1) regardless of the results of the tests.
5 Test results that are protected genetic in-
6 formation shall be subject to the applicable
7 provisions of this subsection.

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

13 “(G) PROTECTED GENETIC INFORMA-
14 TION.—The term ‘protected genetic informa-
15 tion’ means—

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

18 “(ii) information about genetic tests
19 of family members of the individual; or

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

23 (2) LIMITATIONS WITH RESPECT TO DEFINI-
24 TION.—Section 1882(v) of the Social Security Act

1 (42 U.S.C. 1395ss), as added by paragraph (1), is
2 amended by adding at the end the following:

3 “(11) LIMITATIONS.—As defined in paragraph
4 (10)(G), the term protected genetic information shall
5 not include—

6 “(A) information about the sex or age of
7 the individual;

8 “(B) information about chemical, blood, or
9 urine analyses of the individual, unless these
10 analyses are genetic tests; or

11 “(C) information about physical exams of
12 the individual, and other information that indi-
13 cates the current health status of the indi-
14 vidual.”.

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

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

22 (4) EFFECTIVE DATE.—The amendments made
23 by this subsection shall apply with respect to an
24 issuer of a medicare supplemental policy for policy
25 years beginning after October 1, 2002.

1 (c) TRANSITION PROVISIONS.—

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

11 (2) NAIC STANDARDS.—If, not later than June
12 30, 2002, the National Association of Insurance
13 Commissioners (in this subsection referred to as the
14 “NAIC”) modifies its NAIC Model Regulation relat-
15 ing to section 1882 of the Social Security Act (re-
16 ferred to in such section as the 1991 NAIC Model
17 Regulation, as subsequently modified) to conform to
18 the amendments made by this section, such revised
19 regulation incorporating the modifications shall be
20 considered to be the applicable NAIC model regula-
21 tion (including the revised NAIC model regulation
22 and the 1991 NAIC Model Regulation) for the pur-
23 poses of such section.

24 (3) SECRETARY STANDARDS.—If the NAIC
25 does not make the modifications described in para-

1 graph (2) within the period specified in such para-
2 graph, the Secretary of Health and Human Services
3 shall, not later than October 1, 2002, make the
4 modifications described in such paragraph and such
5 revised regulation incorporating the modifications
6 shall be considered to be the appropriate regulation
7 for the purposes of such section.

8 (4) DATE SPECIFIED.—

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

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

16 (ii) October 1, 2002.

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

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

24 (ii) having a legislature which is not
25 scheduled to meet in 2002 in a legislative

1 session in which such legislation may be
2 considered,
3 the date specified in this paragraph is the first
4 day of the first calendar quarter beginning after
5 the close of the first legislative session of the
6 State legislature that begins on or after July 1,
7 2002. For purposes of the previous sentence, in
8 the case of a State that has a 2-year legislative
9 session, each year of such session shall be
10 deemed to be a separate regular session of the
11 State legislature.

12 **TITLE II—PROHIBITION OF EM-**
13 **PLOYMENT DISCRIMINATION**
14 **ON THE BASIS OF PRO-**
15 **TECTED GENETIC INFORMA-**
16 **TION**

17 **SEC. 201. DEFINITIONS.**

18 In this title:

19 (1) EMPLOYEE; EMPLOYER; EMPLOYMENT
20 AGENCY; LABOR ORGANIZATION; MEMBER.—The
21 terms “employee”, “employer”, “employment agen-
22 cy”, and “labor organization” have the meanings
23 given such terms in section 701 of the Civil Rights
24 Act of 1964 (42 U.S.C. 2000e), except that the
25 terms “employee” and “employer” shall also include

1 the meanings given such terms in section 717 of the
2 Civil Rights Act of 1964 (42 U.S.C. 2000e–16). The
3 terms “employee” and “member” include an appli-
4 cant for employment and an applicant for member-
5 ship in a labor organization, respectively.

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

8 (A) the spouse of the individual;

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

12 (C) any other individuals related by blood
13 to the individual or to the spouse or child de-
14 scribed in subparagraph (A) or (B).

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

1 (4) 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 counseling.

6 (5) GENETIC TEST.—

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

12 (B) CERTAIN TESTS.—Notwithstanding
13 subparagraph (A), the conducting of metabolic
14 tests that are not intended to reveal protected
15 genetic information shall not be considered a
16 violation of 203(a)(3), 204(3), 205(3), or
17 206(3) regardless of the results of the tests.
18 Test results that are protected genetic informa-
19 tion shall be subject to the applicable provisions
20 of this title.

21 (6) PROTECTED GENETIC INFORMATION.—The
22 term “protected genetic information” means—

23 (A) information about an individual’s ge-
24 netic tests;

1 (B) information about genetic tests of fam-
2 ily members of the individual; or

3 (C) information about the occurrence of a
4 disease or disorder in family members.

5 **SEC. 202. LIMITATIONS WITH RESPECT TO DEFINITION.**

6 As defined in section 201(6), the term protected ge-
7 netic information shall not include—

8 (1) information about the sex or age of the in-
9 dividual; or

10 (2) information about chemical, blood, or urine
11 analyses of the individual, unless these analyses are
12 genetic tests.

13 **SEC. 203. EMPLOYER PRACTICES.**

14 (a) IN GENERAL.—It shall be an unlawful employ-
15 ment practice for an employer—

16 (1) to fail or refuse to hire or to discharge any
17 individual, or otherwise to discriminate against any
18 individual with respect to the compensation, terms,
19 conditions, or privileges of employment of the indi-
20 vidual, because of protected genetic information with
21 respect to the individual or information about a re-
22 quest for or the receipt of genetic services by such
23 individual or family member of such individual;

24 (2) to limit, segregate, or classify the employees
25 of the employer in any way that would deprive or

1 tend to deprive any individual of employment oppor-
2 tunities or otherwise adversely affect the status of
3 the individual as an employee, because of protected
4 genetic information with respect to the individual, or
5 information about a request for or the receipt of ge-
6 netic services by such individual or family member
7 of such individual; or

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

11 (A) where used for genetic monitoring of
12 biological effects of toxic substances in the
13 workplace, but only if—

14 (i) the employee has provided prior,
15 knowing, voluntary, and written authoriza-
16 tion;

17 (ii) the employee is informed of indi-
18 vidual monitoring results;

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

1 Health Act of 1977 (30 U.S.C. 801 et
2 seq.); and

3 (iv) the employer, excluding any li-
4 censed health care professional that is in-
5 volved in the genetic monitoring program,
6 receives the results of the monitoring only
7 in aggregate terms that do not disclose the
8 identity of specific employees; or

9 (B) where health or genetic services are of-
10 fered by the employer and the employee pro-
11 vides prior, knowing, voluntary, and written au-
12 thorization, and only the employee or family
13 member of such employee receives the results of
14 such services; or

15 (C) with respect to an applicant who has
16 been given a conditional offer of employment or
17 to an employee, an employer may request, re-
18 quire, collect or purchase the information de-
19 scribed in section 201(6)(C) if—

20 (i) the request or requirement is con-
21 sistent with the Americans with Disabil-
22 ities Act of 1990 (42 U.S.C. 12101 et
23 seq.) or the Rehabilitation Act of 1973 (29
24 U.S.C. 701 et seq.);

1 (ii)(I) the information obtained is to
2 be used exclusively to assess whether fur-
3 ther medical evaluation is needed to diag-
4 nose a current disease, or medical condi-
5 tion or disorder; and

6 (II) such current disease, or medical
7 condition or disorder could prevent the ap-
8 plicant or employee from performing the
9 essential functions of the position desired
10 or held; and

11 (III) the information described in
12 such section will not be disclosed to per-
13 sons other than medical personnel involved
14 in or responsible for assessing whether fur-
15 ther medical evaluation is needed to diag-
16 nose a current disease, or medical condi-
17 tion or disorder, except as otherwise per-
18 mitted by this title.

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

23 **SEC. 204. EMPLOYMENT AGENCY PRACTICES.**

24 It shall be an unlawful employment practice for an
25 employment agency—

1 (1) to fail or refuse to refer for employment, or
2 otherwise to discriminate against, any individual be-
3 cause of protected genetic information with respect
4 to the individual (or information about a request for
5 or the receipt of genetic services by such individual
6 or family member of such individual);

7 (2) to limit, segregate, or classify individuals or
8 fail or refuse to refer for employment any individual
9 in any way that would deprive or tend to deprive any
10 individual of employment opportunities or would
11 limit the employment opportunities or otherwise ad-
12 versely affect the status of the individual as an em-
13 ployee, because of protected genetic information with
14 respect to the individual (or information about a re-
15 quest for or the receipt of genetic services by such
16 individual or family member of such individual);

17 (3) to request, require, collect or purchase pro-
18 tected genetic information with respect to an indi-
19 vidual (or information about a request for or the re-
20 ceipt of genetic services by such individual or family
21 member of such individual); or

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

1 **SEC. 205. LABOR ORGANIZATION PRACTICES.**

2 It shall be an unlawful employment practice for a
3 labor organization—

4 (1) to exclude or to expel from the membership
5 of the organization, or otherwise to discriminate
6 against, any individual because of protected genetic
7 information with respect to the individual (or infor-
8 mation about a request for or the receipt of genetic
9 services by such individual or family member of such
10 individual);

11 (2) to limit, segregate, or classify the members
12 of the organization, or fail or refuse to refer for em-
13 ployment any individual, in any way that would de-
14 prive or tend to deprive any individual of employ-
15 ment opportunities, or would limit the employment
16 opportunities or otherwise adversely affect the status
17 of the individual as an employee, because of pro-
18 tected genetic information with respect to the indi-
19 vidual (or information about a request for or the re-
20 ceipt of genetic services by such individual or family
21 member of such individual);

22 (3) to request, require, collect or purchase pro-
23 tected genetic information with respect to an indi-
24 vidual (or information about a request for or the re-
25 ceipt of genetic services by such individual or family
26 member of such individual); or

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

4 **SEC. 206. TRAINING PROGRAMS.**

5 It shall be an unlawful employment practice for any
6 employer, labor organization, or joint labor-management
7 committee controlling apprenticeship or other training or
8 retraining, including on-the-job training programs—

9 (1) to discriminate against any individual be-
10 cause of protected genetic information with respect
11 to the individual (or information about a request for
12 or the receipt of genetic services by such individual),
13 in admission to, or employment in, any program es-
14 tablished to provide apprenticeship or other training
15 or retraining;

16 (2) to limit, segregate, or classify the members
17 of the organization, or fail or refuse to refer for em-
18 ployment any individual, in any way that would de-
19 prive or tend to deprive any individual of employ-
20 ment opportunities, or would limit the employment
21 opportunities or otherwise adversely affect the status
22 of the individual as an employee, because of pro-
23 tected genetic information with respect to the indi-
24 vidual (or information about a request for or receipt

1 of genetic services by such individual or family mem-
 2 ber 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 receipt
 6 of genetic services by such individual or family mem-
 7 ber 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. 207. MAINTENANCE AND DISCLOSURE OF PROTECTED**
 12 **GENETIC INFORMATION.**

13 (a) MAINTENANCE OF PROTECTED GENETIC INFOR-
 14 MATION.—If an employer possesses protected genetic in-
 15 formation about an employee (or information about a re-
 16 quest for or receipt of genetic services by such employee
 17 or family member of such employee), such information
 18 shall be treated and maintained as part of the employee’s
 19 confidential medical records.

20 (b) DISCLOSURE OF PROTECTED GENETIC INFORMA-
 21 TION.—An employer shall not disclose protected genetic
 22 information (or information about a request for or receipt
 23 of genetic services by such employee or family member of
 24 such employee) except—

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

3 (2) to an occupational or other health re-
4 searcher if the research is conducted in compliance
5 with the regulations and protections provided for
6 under part 46 of title 45, Code of Federal Regula-
7 tions;

8 (3) under legal compulsion of a Federal court
9 order, except that if the court order was secured
10 without the knowledge of the individual to whom the
11 information refers, the employer shall provide the in-
12 dividual with adequate notice to challenge the court
13 order unless the court order also imposes confiden-
14 tiality requirements; and

15 (4) to government officials who are inves-
16 tigating compliance with this Act if the information
17 is relevant to the investigation.

18 **SEC. 208. CIVIL ACTION.**

19 (a) **IN GENERAL.**—One or more employees, members
20 of a labor organization, or participants in training pro-
21 grams or a labor organization may bring an action in a
22 Federal or State court of competent jurisdiction against
23 an employer, employment agency, labor organization, or
24 joint labor-management committee or training program
25 who commits a violation of this title.

1 (b) ENFORCEMENT BY THE EQUAL EMPLOYMENT
2 OPPORTUNITY COMMISSION.—

3 (1) IN GENERAL.—The powers, remedies, and
4 procedures set forth in sections 705, 706, 707, 709,
5 710, and 717 of the Civil Rights Act of 1964 (42
6 U.S.C. 2000e-4, 2000e-5, 2000e-6, 2000e-8,
7 2000e-9, and 2000e-16) shall be the powers, rem-
8 edies, and procedures provided to the Equal Employ-
9 ment Opportunity Commission to enforce this title.
10 The Commission may promulgate regulations to im-
11 plement these powers, remedies, and procedures.

12 (2) EXHAUSTION OF REMEDIES.—Nothing in
13 this subsection shall be constructed to require that
14 an individual exhaust the administrative remedies
15 available through the Equal Employment Oppor-
16 tunity Commission prior to commencing a civil ac-
17 tion under this section, except that if an individual
18 files a charge of discrimination with the Commission
19 that alleges a violation of this title, the individual
20 shall exhaust the administrative remedies available
21 through the Commission prior to commencing a civil
22 action under this section.

23 (c) REMEDY.—A Federal or State court may award
24 any appropriate legal or equitable relief under this section.

1 Such relief may include a requirement for the payment
2 of attorney's fees and costs, including the cost of experts.

3 **SEC. 209. CONSTRUCTION.**

4 Nothing in this title shall be construed to—

5 (1) limit the rights or protections of an indi-
6 vidual under the Americans with Disabilities Act of
7 1990 (42 U.S.C. 12101 et seq.), including coverage
8 afforded to individuals under section 102 of such
9 Act;

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

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

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

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

1 **SEC. 210. AUTHORIZATION OF APPROPRIATIONS.**

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

4 **SEC. 211. EFFECTIVE DATE.**

5 This title shall become effective on October 1, 2002.

6 **TITLE III—MISCELLANEOUS PROVISIONS**

7 **SEC. 301. SEVERABILITY.**

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

○