

107TH CONGRESS
1ST SESSION

H. R. 602

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

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 13, 2001

Ms. SLAUGHTER (for herself, Mrs. MORELLA, Mr. ABERCROMBIE, Mr. ACKERMAN, Mr. ALLEN, Mr. BALDACCI, Ms. BALDWIN, Mr. BENTSEN, Ms. BERKLEY, Mr. BERMAN, Mr. BLAGOJEVICH, Mr. BLUMENAUER, Mr. BONIOR, Mr. BORKSI, Mr. BOUCHER, Mr. BOYD, Mr. BRADY of Pennsylvania, Mr. BURTON of Indiana, Mr. CALVERT, Mrs. CAPPES, Mr. CAPUANO, Mr. CARDIN, Ms. CARSON of Indiana, Mrs. CHRISTENSEN, Mr. COSTELLO, Mr. COYNE, Mr. CRAMER, Mr. DAVIS of Illinois, Mr. DEFAZIO, Ms. DEGETTE, Mr. DELAHUNT, Ms. DELAUBO, Mr. DICKS, Mr. DOYLE, Mr. DUNCAN, Mr. EDWARDS, Ms. ESHOO, Mr. ETHERIDGE, Mr. EVANS, Mr. FARR of California, Mr. FATTAH, Mr. FILNER, Mr. FORD, Mr. FRANK, Mr. FRELINGHUYSEN, Mr. FROST, Mr. GALLEGLY, Mr. GEPHARDT, Mr. GILCHREST, Mr. GILMAN, Mr. GREEN of Texas, Mr. HALL of Ohio, Mr. HILLIARD, Mr. HINCHEY, Mr. HOEFFEL, Mr. HOLDEN, Mr. HOLT, Ms. HOOLEY of Oregon, Mr. HORN, Mr. INSLEE, Mr. JEFFERSON, Mrs. JONES of Ohio, Mr. KANJORSKI, Ms. KAPTUR, Mrs. KELLY, Mr. KILDEE, Ms. KILPATRICK, Mr. KING, Mr. KLECKZA, Mr. KOLBE, Mr. KUCINICH, Mr. LAMPSON, Mr. LANTOS, Mr. LARSON of Connecticut, Ms. LEE, Mr. LEVIN, Ms. LOFGREN, Mrs. LOWEY, Mr. LUTHER, Mrs. McCARTHY of New York, Ms. McCARTHY of Missouri, Ms. MCCOLLUM, Mr. McDERMOTT, Mr. McGOVERN, Mr. MCHUGH, Mr. McNULTY, Mrs. MALONEY of New York, Mr. MALONEY of Connecticut, Mr. MARKEY, Mr. MASCARA, Mr. MATSUI, Mr. MEEHAN, Mrs. MEEK of Florida, Mr. MEEKS of New York, Mr. MENENDEZ, Ms. MILLENDER-MCDONALD, Mr. GEORGE MILLER of California, Mrs. MINK of Hawaii, Mr. MOAKLEY, Mr. MOORE, Mr. MORAN of Virginia, Mr. MURTHA, Mr. NADLER, Mrs. NAPOLITANO, Mr. NEY, Ms. NORTON, Mr. OBERSTAR, Mr. OBEY, Mr. OLVER, Mr. PALLONE, Mr. PASCRELL, Mr. PAYNE, Ms. PELOSI, Mr. PHELPS, Mr. PRICE of North Carolina, Mr. RANGEL, Mr. REYES, Ms. RIVERS, Ms. ROS-LEHTINEN, Mrs. ROUKEMA, Ms. ROYBAL-ALLARD, Mr. RUSH, Mr. SANDERS, Mr. SANDLIN, Ms. SCHAKOWSKY, Mr. SCOTT, Mr. SERRANO, Mr. SHERMAN, Mr. SISISKY, Mr. SKELTON, Mr. SMITH of Washington, Mr. SNYDER, Mr. SPRATT, Mr. STARK, Mr. STENHOLM, Mr. STRICKLAND, Mr. STUPAK, Mrs. TAUSCHER, Mr. THOMPSON

of Mississippi, Mrs. THURMAN, Mr. TIERNEY, Mr. TRAFICANT, Mr. UDALL of Colorado, Mr. UDALL of New Mexico, Mr. VISCLOSKY, Mr. WALSH, Ms. WATERS, Mr. WAXMAN, Mr. WEINER, Mr. WEXLER, Mr. WOLF, 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.**

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

7 **TITLE I—PROHIBITION OF
8 HEALTH INSURANCE DIS-
9 CRIMINATION ON THE BASIS
10 OF PROTECTED GENETIC IN-
11 FORMATION**

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

14 (a) PROHIBITION OF HEALTH INSURANCE DISCRIMI-
15 NATION ON THE BASIS OF GENETIC SERVICES OR PRO-
16 TECTED GENETIC INFORMATION.—

10 (A) IN GENERAL.—Subpart B of part 7 of
11 subtitle B of title I of the Employee Retirement
12 Income Security Act of 1974 (29 U.S.C. 1185
13 et seq.) is amended by adding at the end the
14 following:

15 "SEC. 714. PROHIBITING DISCRIMINATION AGAINST
16 GROUPS ON THE BASIS OF PROTECTED GE-
17 NETIC INFORMATION.

18 “A group health plan, and a health insurance issuer
19 offering group health insurance coverage in connection
20 with 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).”.

1 (B) CONFORMING AMENDMENTS.—

2 (i) Section 702(b)(2)(A) of the Em-
3 ployee Retirement Income Security Act of
4 1974 (29 U.S.C. 1182(b)) is amended to
5 read as follows:6 “(A) to restrict the amount that an em-
7 ployer may be charged for coverage under a
8 group health plan, except as provided in section
9 714; or”.10 (ii) Section 732(a) of the Employee
11 Retirement Income Security Act of 1974
12 (29 U.S.C. 1191a(a)) is amended by strik-
13 ing “section 711” and inserting “sub-
14 sections (a)(1)(F), (b) (with respect to
15 cases relating to genetic information or in-
16 formation about a request or receipt of ge-
17 netic services by an individual or family
18 member of such individual), (c), (d), (e),
19 (f), or (g) of section 702, section 711 and
20 section 714”.21 (b) LIMITATIONS ON GENETIC TESTING AND ON
22 COLLECTION AND DISCLOSURE OF PROTECTED GENETIC
23 INFORMATION.—Section 702 of the Employee Retirement
24 Income Security Act of 1974 (29 U.S.C. 1182) is amended
25 by adding at the end the following:

1 “(c) GENETIC TESTING.—

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

8 “(2) RULE OF CONSTRUCTION.—Nothing in
9 this part shall be construed to limit the authority of
10 a health care professional, who is providing treat-
11 ment with respect to an individual and who is em-
12 ployed by a group health plan or a health insurance
13 issuer, to request that such individual or family
14 member of such individual undergo a genetic test.
15 Such a health care professional shall not require
16 that such individual or family member undergo a ge-
17 netic test.

18 “(d) COLLECTION OF PROTECTED GENETIC INFOR-
19 MATION.—Except as provided in subsections (f) and (g),
20 a group health plan, or a health insurance issuer offering
21 health insurance coverage in connection with a group
22 health plan, shall not request, require, collect, or purchase
23 protected genetic information concerning an individual (or
24 information about a request for or the receipt of genetic

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

3 “(e) DISCLOSURE OF PROTECTED GENETIC INFOR-
4 MATION.—A group health plan, or a health insurance
5 issuer offering health insurance coverage in connection
6 with a group health plan, shall not disclose protected ge-
7 netic information about an individual (or information
8 about a request for or the receipt of genetic services by
9 such individual or family member of such individual) to—

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

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

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

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

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

24 “(f) INFORMATION FOR PAYMENT FOR GENETIC
25 SERVICES.—

1 “(1) IN GENERAL.—With respect to payment
2 for genetic services conducted concerning an indi-
3 vidual or the coordination of benefits, a group health
4 plan, or a health insurance issuer offering group
5 health insurance coverage in connection with a group
6 health plan, may request that the individual provide
7 the plan or issuer with evidence that such services
8 were performed.

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

11 “(A) permit a group health plan or health
12 insurance issuer to request (or require) the re-
13 sults of the services referred to in such para-
14 graph; or

15 “(B) require that a group health plan or
16 health insurance issuer make payment for serv-
17 ices described in such paragraph where the in-
18 dividual involved has refused to provide evi-
19 dence of the performance of such services pur-
20 suant to a request by the plan or issuer in ac-
21 cordance with such paragraph.

22 “(g) INFORMATION FOR PAYMENT OF OTHER
23 CLAIMS.—With respect to the payment of claims for bene-
24 fits other than genetic services, a group health plan, or
25 a health insurance issuer offering group health insurance

1 coverage in connection with a group health plan, may re-
2 quest that an individual provide protected genetic informa-
3 tion so long as such information—

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

5 “(2) is limited to information that is directly re-
6 lated to and necessary for the payment of such claim
7 and the claim would otherwise be denied but for the
8 protected genetic information; and

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

13 “(h) RULES OF CONSTRUCTION.—

14 “(1) COLLECTION OR DISCLOSURE AUTHORIZED
15 BY INDIVIDUAL.—The provisions of subsections (d)
16 (regarding collection) and (e) shall not apply to an
17 individual if the individual (or legal representative of
18 the individual) provides prior, knowing, voluntary,
19 and written authorization for the collection or diselo-
20 sure of protected genetic information.

21 “(2) DISCLOSURE FOR HEALTH CARE TREAT-
22 MENT.—Nothing in this section shall be construed to
23 limit or restrict the disclosure of protected genetic
24 information from a health care provider to another

1 health care provider for the purpose of providing
2 health care treatment to the individual involved.

3 “(i) DEFINITIONS.—In this section:

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

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

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

15 “(n) VIOLATION OF GENETIC DISCRIMINATION OR
16 GENETIC DISCLOSURE PROVISIONS.—In any action under
17 this section against any administrator of a group health
18 plan, or health insurance issuer offering group health in-
19 surance coverage in connection with a group health plan
20 (including any third party administrator or other person
21 acting for or on behalf of such plan or issuer) alleging
22 a violation of subsection (a)(1)(F), (b) (with respect to
23 cases relating to genetic information or information about
24 a request or receipt of genetic services by an individual
25 or family member of such individual), (c), (d), (e), (f), or

1 (g) of section 702, or section 714, the court may award
2 any appropriate legal or equitable relief. Such relief may
3 include a requirement for the payment of attorney's fees
4 and costs, including the costs of expert witnesses.

5 “(o) CIVIL PENALTY.—The monetary provisions of
6 section 308(b)(2)(C) of Public Law 101–336 (42 U.S.C.
7 12188(b)(2)(C)) shall apply for purposes of the Secretary
8 enforcing the provisions referred to in subsection (n), ex-
9 cept that any such relief awarded shall be paid only into
10 the general fund of the Treasury.”.

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

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

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

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

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

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

12 (e) DEFINITIONS.—Section 733(d) of the Employee
13 Retirement Income Security Act of 1974 (29 U.S.C.
14 1191b(d)) is amended by adding at the end the following:

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

17 “(A) the spouse of the individual;

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

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

24 “(6) GENETIC INFORMATION.—The term ‘ge-
25 netic information’ means information about genes,

1 gene products, or inherited characteristics that may
2 derive from an individual or a family member of
3 such individual (including information about a re-
4 quest for or the receipt of genetic services by such
5 individual or family member of such individual).

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

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

15 “(9) PROTECTED GENETIC INFORMATION.—

16 “(A) IN GENERAL.—The term ‘protected
17 genetic information’ means—

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

20 “(ii) information about genetic tests
21 of family members of the individual; or

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

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

3 “(i) information about the sex or age
4 of the individual;

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

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

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

22 (g) EFFECTIVE DATE.—

23 (1) IN GENERAL.—Except as provided in this
24 section, this section and the amendments made by
25 this section shall apply with respect to group health

1 plans for plan years beginning after October 1,
2 2002.

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

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

17 (B) October 1, 2002.

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

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

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

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

23 “(2) any other group health plan or health in-
24 surance issuer or any insurance agent, third party

1 administrator, or other person subject to regulation
2 under State insurance laws;

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

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

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

10 “(f) INFORMATION FOR PAYMENT FOR GENETIC
11 SERVICES.—

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

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

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

1 “(B) require that a group health plan or
2 health insurance issuer make payment for serv-
3 ices described in such paragraph where the in-
4 dividual involved has refused to provide evi-
5 dence of the performance of such services pur-
6 suant to a request by the plan or issuer in ac-
7 cordance with such paragraph.

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

1 “(1) COLLECTION OR DISCLOSURE AUTHORIZED
2 BY INDIVIDUAL.—The provisions of subsections (d)
3 (regarding collection) and (e) shall not apply to an
4 individual if the individual (or legal representative of
5 the individual) provides prior, knowing, voluntary,
6 and written authorization for the collection or diselo-
7 sure 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 “(i) DEFINITIONS.—In this section:

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

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.”.

24 (3) DEFINITIONS.—Section 2791(d) of the Pub-
25 lic Health Service Act (42 U.S.C. 300gg–91(d)) is

1 amended by adding at the end the following new
2 paragraphs:

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

5 “(A) the spouse of the individual;

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

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

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

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

24 “(18) GENETIC TEST.—The term ‘genetic test’
25 means the analysis of human DNA, RNA, chro-

1 mosomes, proteins, and metabolites that detect
2 genotypes, mutations, or chromosomal changes.

3 “(19) PROTECTED GENETIC INFORMATION.—

4 “(A) IN GENERAL.—The term ‘protected
5 genetic information’ means—

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

8 “(ii) information about genetic tests
9 of family members of the individual; or

10 “(iii) information about the occur-
11 rence of a disease or disorder in family
12 members.

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

15 “(i) information about the sex or age
16 of the individual;

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

20 “(iii) information about physical
21 exams of the individual, and other informa-
22 tion that indicates the current health sta-
23 tus of the individual.”.

24 (b) AMENDMENT RELATING TO THE INDIVIDUAL
25 MARKET.—The first subpart 3 of part B of title XXVII

1 of the Public Health Service Act (42 U.S.C. 300gg–51 et
2 seq.) is amended—

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

4 and

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

6 **“SEC. 2753. PROHIBITION OF HEALTH INSURANCE DIS-**
7 **CRIMINATION AGAINST INDIVIDUALS ON THE**
8 **BASIS OF PROTECTED GENETIC INFORMA-**
9 **TION.**

10 “(a) INELIGIBILITY TO ENROLL.—A health insur-
11 ance issuer offering health insurance coverage in the indi-
12 vidual market shall not establish rules for eligibility to en-
13 roll in individual health insurance coverage that are based
14 on protected genetic information concerning the individual
15 (or information about a request for or the receipt of ge-
16 netic services by such individual or family member of such
17 individual).

18 “(b) IN PREMIUM RATES.—A health insurance issuer
19 offering health insurance coverage in the individual mar-
20 ket shall not adjust premium rates on the basis of pro-
21 tected genetic information concerning an individual (or in-
22 formation about a request for or the receipt of genetic
23 services by such individual or family member of such indi-
24 vidual).

1 **“SEC. 2754. LIMITATIONS ON GENETIC TESTING AND ON**
2 **COLLECTION AND DISCLOSURE OF PRO-**
3 **TECTED GENETIC INFORMATION.**

4 “(a) GENETIC TESTING.—

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

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

21 “(b) COLLECTION OF PROTECTED GENETIC INFOR-
22 MATION.—Except as provided in subsections (d) and (e),
23 a health insurance issuer offering health insurance cov-
24 erage in the individual market shall not request, require,
25 collect, or purchase protected genetic information con-
26 cerning an individual (or information about a request for

1 or the receipt of genetic services by such individual or fam-
2 ily member of such individual).

3 “(c) DISCLOSURE OF PROTECTED GENETIC INFOR-
4 MATION.—A health insurance issuer offering health insur-
5 ance coverage in the individual market shall not disclose
6 protected genetic information about 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) to—

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

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

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

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

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

24 “(d) INFORMATION FOR PAYMENT FOR GENETIC
25 SERVICES.—

1 “(1) IN GENERAL.—With respect to payment
2 for genetic services conducted concerning an indi-
3 vidual or the coordination of benefits, a health insur-
4 ance issuer offering health insurance coverage in the
5 individual market may request that the individual
6 provide the plan or issuer with evidence that such
7 services were performed.

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

10 “(A) permit a health insurance issuer to
11 request (or require) the results of the services
12 referred to in such paragraph; or

13 “(B) require that a health insurance issuer
14 make payment for services described in such
15 paragraph where the individual involved has re-
16 fused to provide evidence of the performance of
17 such services pursuant to a request by the plan
18 or issuer in accordance with such paragraph.

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

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

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

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

9 “(f) RULES OF CONSTRUCTION.—

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

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

23 “(g) DEFINITIONS.—In this section:

24 “(1) CONTROLLED GROUP.—The term ‘con-
25 trolled group’ means any group treated as a single

1 employer under subsection (b), (c), (m), or (o) of
2 section 414 of the Internal Revenue Code of 1986.

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

8 (c) ENFORCEMENT.—

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

12 “(c) VIOLATION OF GENETIC DISCRIMINATION OR
13 GENETIC DISCLOSURE PROVISIONS.—In any action under
14 this section against any administrator of a group health
15 plan, or health insurance issuer offering group health in-
16 surance coverage in connection with a group health plan
17 (including any third party administrator or other person
18 acting for or on behalf of such plan or issuer) alleging
19 a violation of subsections (a)(1)(F), (b) (with respect to
20 cases relating to genetic information or information about
21 a request or receipt of genetic services by an individual
22 or family member of such individual), (c), (d), (e), (f), or
23 (g) of section 2702 and section 2707 the court may award
24 any appropriate legal or equitable relief. Such relief may

1 include a requirement for the payment of attorney's fees
2 and costs, including the costs of expert witnesses.

3 “(d) CIVIL PENALTY.—The monetary provisions of
4 section 308(b)(2)(C) of Public Law 101–336 (42 U.S.C.
5 12188(b)(2)(C)) shall apply for purposes of the Secretary
6 enforcing the provisions referred to in subsection (c), ex-
7 cept that any such relief awarded shall be paid only into
8 the general fund of the Treasury.”.

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

12 “(c) VIOLATION OF GENETIC DISCRIMINATION OR
13 GENETIC DISCLOSURE PROVISIONS.—In any action under
14 this section against any health insurance issuer offering
15 health insurance coverage in the individual market (in-
16 cluding any other person acting for or on behalf of such
17 issuer) alleging a violation of sections 2753 and 2754 the
18 court in which the action is commenced may award any
19 appropriate legal or equitable relief. Such relief may in-
20 clude a requirement for the payment of attorney's fees and
21 costs, including the costs of expert witnesses.

22 “(d) CIVIL PENALTY.—The monetary provisions of
23 section 308(b)(2)(C) of Public Law 101–336 (42 U.S.C.
24 12188(b)(2)(C)) shall apply for purposes of the Secretary
25 enforcing the provisions referred to in subsection (c), ex-

1 cept that any such relief awarded shall be paid only into
2 the general fund of the Treasury.”.

3 (d) PREEMPTION.—

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

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

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

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

19 “(1) protects the confidentiality of genetic in-
20 formation (including information about a request for
21 or the receipt of genetic services by an individual or
22 a family member of such individual) or the privacy
23 of an individual or a family member of the individual
24 with respect to genetic information (including infor-
25 mation about a request for or the receipt of genetic

1 services by an individual or a family member of such
2 individual) than does this part; or

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

5 (2) INDIVIDUAL MARKET.—Section 2762 of the
6 Public Health Service Act (42 U.S.C. 300gg-46) is
7 amended—

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

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

12 “(c) SPECIAL RULE IN CASE OF GENETIC INFORMA-
13 TION.—With respect to individual health insurance cov-
14 erage offered by a health insurance issuer, the provisions
15 of this part (or part C insofar as it applies to this part)
16 relating to genetic information (including information
17 about a request for or the receipt of genetic services by
18 an individual or a family member of such individual) shall
19 not be construed to supersede any provision of State law
20 (as defined in section 2723(d)) which establishes, imple-
21 ments, or continues in effect a standard, requirement, or
22 remedy that more completely—

23 “(1) protects the confidentiality of genetic in-
24 formation (including information about a request for
25 or the receipt of genetic services of an individual or

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

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

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

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

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

20 “(D) ELECTION NOT APPLICABLE TO RE-
21 QUIREMENTS CONCERNING GENETIC INFORMA-
22 TION.—The election described in subparagraph
23 (A) shall not be available with respect to the
24 provisions of subsections (a)(1)(F), (c), (d), (e),
25 (f), and (g) of section 2702 and section 2707,

1 and the provisions of section 2702(b) to the ex-
2 tent that they apply to genetic information (or
3 information about a request for or the receipt
4 of genetic services by an individual or a family
5 member of such individual).”.

6 (f) AMENDMENT CONCERNING SUPPLEMENTAL EX-
7 CEPTED BENEFITS.—

8 (1) GROUP MARKET.—Section 2721(d)(3) of
9 the Public Health Service Act (42 U.S.C. 300gg–
10 23(d)(3)) is amended by inserting “, other than the
11 requirements of subsections (a)(1)(F), (b) (in cases
12 relating to genetic information or information about
13 a request for or the receipt of genetic services by an
14 individual or a family member of such individual),
15 (c), (d), (e), (f) and (g) of section 2702 and section
16 2707,” after “The requirements of this part”.

17 (2) INDIVIDUAL MARKET.—Section 2763(b) of
18 the Public Health Service Act (42 U.S.C. 300gg–
19 47(b)) is amended—

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

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

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

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

4 (g) EFFECTIVE DATE.—

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

7 (A) group health plans, and health insur-
8 ance coverage offered in connection with group
9 health plans, for plan years beginning; and

10 (B) health insurance coverage offered,
11 sold, issued, renewed, in effect, or operated in
12 the individual market, after;

13 October 1, 2002.

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

22 (A) the date on which the last of the col-
23 lective bargaining agreements relating to the
24 plan terminates (determined without regard to

1 any extension thereof agreed to after the date
2 of the enactment of this Act); or
3 (B) October 1, 2002.

4 For purposes of subparagraph (A), any plan amend-
5 ment made pursuant to a collective bargaining
6 agreement relating to the plan which amends the
7 plan solely to conform to any requirement of the
8 amendments made by this section shall not be treat-
9 ed as a termination of such collective bargaining
10 agreement.

11 **SEC. 103. AMENDMENTS TO INTERNAL REVENUE CODE OF**
12 **1986.**

13 (a) PROHIBITION OF HEALTH INSURANCE DISCRIMI-
14 NATION ON THE BASIS OF GENETIC SERVICES OR PRO-
15 TECTED GENETIC INFORMATION.—

16 (1) NO ENROLLMENT RESTRICTION FOR GE-
17 NETIC SERVICES.—Section 9802(a)(1)(F) of the In-
18 ternal Revenue Code of 1986 is amended by insert-
19 ing before the period “(or information about a re-
20 quest for or the receipt of genetic services by such
21 individual or family member of such individual)”.
22 (2) NO DISCRIMINATION IN GROUP RATE BASED
23 ON PROTECTED GENETIC INFORMATION.—

1 (A) IN GENERAL.—Subchapter B of chapter 100 of the Internal Revenue Code of 1986
2 is amended by adding at the end the following:

4 **“SEC. 9813. PROHIBITING DISCRIMINATION AGAINST**
5 **GROUPS ON THE BASIS OF PROTECTED GE-**
6 **NETIC INFORMATION.**

7 “A group health plan shall not deny eligibility to a
8 group or adjust premium or contribution rates for a group
9 on the basis of protected genetic information concerning
10 an individual in the group (or information about a request
11 for or the receipt of genetic services by such individual
12 or family member of such individual).”.

13 (B) CONFORMING AMENDMENTS.—

14 (i) Section 9802(b)(2)(A) of the Inter-
15 nal Revenue Code of 1986 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 9813; or”.

21 (ii) Section 9831(a) of the Internal
22 Revenue Code of 1986 is amended by in-
23 serting “(other than subsections (a)(1)(F),
24 (b) (with respect to cases relating to ge-
25 netic information or information about a

1 request or receipt of genetic services by an
2 individual or family member of such indi-
3 vidual), (d) (e), (f), (g) or (h) of section
4 9802 or section 9813) after “chapter”.

5 (b) LIMITATIONS ON GENETIC TESTING AND ON
6 COLLECTION AND DISCLOSURE OF PROTECTED GENETIC
7 INFORMATION.—Section 9802 of the Internal Revenue
8 Code of 1986 is amended by adding at the end the fol-
9 lowing:

10 “(d) GENETIC TESTING.—

11 “(1) LIMITATION ON REQUESTING OR REQUIR-
12 ING GENETIC TESTING.—A group health plan may
13 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 chapter shall be construed to limit the authority
17 of 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, to request that such
20 individual or family member of such individual un-
21 dergo a genetic test. Such a health care professional
22 shall not require that such individual or family mem-
23 ber undergo a genetic test.

24 “(e) COLLECTION OF PROTECTED GENETIC INFOR-
25 MATION.—Except as provided in subsections (g) and (h),

1 a group health plan shall not request, require, collect, or
2 purchase protected genetic information concerning an in-
3 dividual (or information about a request for or the receipt
4 of genetic services by such individual or family member
5 of such individual).

6 “(f) DISCLOSURE OF PROTECTED GENETIC INFOR-
7 MATION.—A group health plan shall not disclose protected
8 genetic information about an individual (or information
9 about a request for or the receipt of genetic services by
10 such individual or family member of such individual) to—

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

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

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

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

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

1 “(g) INFORMATION FOR PAYMENT FOR GENETIC
2 SERVICES.—

3 “(1) IN GENERAL.—With respect to payment
4 for genetic services conducted concerning an indi-
5 vidual or the coordination of benefits, a group health
6 plan may request that the individual provide the
7 plan with evidence that such services were per-
8 formed.

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

11 “(A) permit a group health plan to request
12 (or require) the results of the services referred
13 to in such paragraph; or

14 “(B) require that a group health plan
15 make payment for services described in such
16 paragraph where the individual involved has re-
17 fused to provide evidence of the performance of
18 such services pursuant to a request by the plan
19 in accordance with such paragraph.

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

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

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

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

9 “(i) RULES OF CONSTRUCTION.—

10 “(1) COLLECTION OR DISCLOSURE AUTHORIZED
11 BY INDIVIDUAL.—The provisions of subsections (e)
12 (regarding collection) and (f) shall not apply to an
13 individual if the individual (or legal representative
14 of, the individual) provides prior, knowing, vol-
15 untary, and written authorization for the collection
16 or disclosure of protected genetic information.

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

23 “(j) DEFINITIONS.—In this section:

24 “(1) CONTROLLED GROUP.—The term ‘con-
25 trolled group’ means any group treated as a single

1 employer under subsections (b), (c), (m), or (o) of
2 section 414.

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

8 (c) DEFINITIONS.—Section 9832(d) of the Internal
9 Revenue Code of 1986 is amended by adding at the end
10 the following:

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

13 “(A) the spouse of the individual;

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

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

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

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

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

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

12 “(10) PROTECTED GENETIC INFORMATION.—

13 “(A) IN GENERAL.—The term ‘protected
14 genetic information’ means—

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

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

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

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

24 “(i) information about the sex or age
25 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 (d) EFFECTIVE DATE.—

9 (1) IN GENERAL.—Except as provided in this
10 section, this section and the amendments made by
11 this section shall apply with respect to group health
12 plans for plan years beginning after October 1,
13 2002.

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

23 (A) the date on which the last of the col-
24 lective bargaining agreements relating to the
25 plan terminates (determined without regard to

1 any extension thereof agreed to after the date
2 of the enactment of this Act), or
3 (B) October 1, 2002.

4 For purposes of subparagraph (A), any plan amend-
5 ment made pursuant to a collective bargaining
6 agreement relating to the plan which amends the
7 plan solely to conform to any requirement of the
8 amendments made by this section shall not be treat-
9 ed as a termination of such collective bargaining
10 agreement.

11 SEC. 104. AMENDMENTS TO TITLE XVIII OF THE SOCIAL SE-

12 CURIITY ACT RELATING TO MEDIGAP.

13 (a) NONDISCRIMINATION.—

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

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

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

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

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

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

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

16 “(v) LIMITATIONS ON GENETIC TESTING AND ON
17 COLLECTION AND DISCLOSURE OF PROTECTED GENETIC
18 INFORMATION.—

19 “(1) GENETIC TESTING.—

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

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

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

19 “(3) DISCLOSURE OF PROTECTED GENETIC IN-
20 FORMATION.—An issuer of a medicare supplemental
21 policy shall not disclose protected genetic informa-
22 tion about an individual (or information about a re-
23 quest for or the receipt of genetic services by such
24 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.—In any ac-
23 tion under this subsection against any administrator
24 of a medicare supplemental policy (including any
25 third party administrator or other person acting for

1 or on behalf of such policy) alleging a violation of
2 this subsection, the court may award any appropriate legal or equitable relief. Such relief may include a requirement for the payment of attorney's fees and costs, including the costs of expert witnesses.

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

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

22 “(A) protects the confidentiality of genetic
23 information (including information about a re-
24 quest for, or the receipt of, genetic services by
25 an individual or a family member of such indi-

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

7 “(B) prohibits discrimination on the basis
8 of genetic information than does this sub-
9 section.

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

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

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

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

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

15 “(E) GENETIC TEST.—The term ‘genetic
16 test’ means the analysis of human DNA, RNA,
17 chromosomes, proteins, and metabolites that de-
18 tect genotypes, mutations, or chromosomal
19 changes.

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

1 “(G) PROTECTED GENETIC INFORMATION.—

2

3 “(i) IN GENERAL.—The term ‘protected genetic information’ means—

4

5 “(I) information about an individual’s genetic tests;

6

7 “(II) information about genetic tests of family members of the individual; or

8

9

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

11

12

13 “(ii) LIMITATIONS.—The term ‘protected genetic information’ shall not include—

14

15

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

17

18

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

20

21

22 “(III) information about physical exams of the individual, and other information that indicates the current health status of the individual.”.

23

24

25

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

12 (c) TRANSITION PROVISIONS.—

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

19 (4) DATE SPECIFIED.—

20 (A) IN GENERAL.—Subject to subparagraph
21 graph (B), the date specified in this paragraph
22 for a State is the earlier of—
23 (i) the date the State changes its stat-
24 utes or regulations to conform its regu-

3 (ii) October 1, 2002.

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

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

11 (ii) having a legislature which is not
12 scheduled to meet in 2002 in a legislative
13 session in which such legislation may be
14 considered,

15 the date specified in this paragraph is the first
16 day of the first calendar quarter beginning after
17 the close of the first legislative session of the
18 State legislature that begins on or after July 1,
19 2002. For purposes of the previous sentence, in
20 the case of a State that has a 2-year legislative
21 session, each year of such session shall be
22 deemed to be a separate regular session of the
23 State legislature.

1 **TITLE II—PROHIBITION OF EM-**
2 **PLOYMENT DISCRIMINATION**
3 **ON THE BASIS OF PRO-**
4 **TECTED GENETIC INFORMA-**
5 **TION**

6 **SEC. 201. DEFINITIONS.**

7 In this title:

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

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

22 (A) the spouse of the individual;
23 (B) a dependent child of the individual, in-
24 cluding a child who is born to or placed for
25 adoption with the individual; or

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

19 (5) GENETIC TEST.—The term “genetic test”
20 means the analysis of human DNA, RNA, chro-
21 mosomes, proteins, and metabolites that detect
22 genotypes, mutations, or chromosomal changes.

23 (6) PROTECTED GENETIC INFORMATION.—

24 (A) IN GENERAL.—The term “protected
25 genetic information” means—

18 SEC. 202. EMPLOYER PRACTICES.

19 (a) IN GENERAL.—It shall be an unlawful employ-
20 ment practice for an employer—
21 (1) to fail or refuse to hire or to discharge any
22 individual, or otherwise to discriminate against any
23 individual with respect to the compensation, terms,
24 conditions, or privileges of employment of the indi-
25 vidual, because of protected genetic information with

1 respect to the individual (or information about a re-
2 quest for or the receipt of genetic services by such
3 individual or family member of such individual;

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

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

16 (A) where used for genetic monitoring of
17 biological effects of toxic substances in the
18 workplace, but only if—

19 (i) the employee has provided prior,
20 knowing, voluntary, and written authoriza-
21 tion;

22 (ii) the employee is informed of indi-
23 vidual monitoring results;

24 (iii) the monitoring conforms to any
25 genetic monitoring regulations that may be

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

13 (B) where genetic services are offered by
14 the employer and the employee provides prior,
15 knowing, voluntary, and written authorization,
16 and only the employee or family member of
17 such employee receives the results of such serv-
18 ices.

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

23 SEC. 203. EMPLOYMENT AGENCY PRACTICES.

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

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);

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

1 **SEC. 204. 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

4 SEC. 205. 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—

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. 206. 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 or 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;

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

18 SEC. 207. CIVIL ACTION.

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

1 (b) ENFORCEMENT BY THE EQUAL EMPLOYMENT
2 OPPORTUNITY COMMISSION.—The powers, remedies, and
3 procedures set forth in sections 705, 706, 707, 709, 710,
4 and 717 of the Civil Rights Act of 1964 (42 U.S.C.
5 2000e-4, 2000e-5, 2000e-6, 2000e-8, 2000e-9, and
6 2000e-16) shall be the powers, remedies, and procedures
7 provided to the Equal Employment Opportunity Commis-
8 sion to enforce this title. The Commission may promulgate
9 regulations to implement these powers, remedies, and pro-
10 cedures.

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

15 **SEC. 208. CONSTRUCTION.**

16 Nothing in this title shall be construed to—

17 (1) limit the rights or protections of an indi-
18 vidual under the Americans with Disabilities Act of
19 1990 (42 U.S.C. 12101 et seq.), including coverage
20 afforded to individuals under section 102 of such
21 Act;

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

5 (4) apply to the Armed Forces Repository of
6 Specimen Samples for the Identification of Remains;
7 or

13 SEC. 209. AUTHORIZATION OF APPROPRIATIONS.

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

16 SEC. 210. EFFECTIVE DATE.

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

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