# S. 1322

To prohibit health insurance and employment discrimination against individuals and their family members on the basis of predictive genetic information or genetic services.

## IN THE SENATE OF THE UNITED STATES

July 1, 1999

Mr. Daschle (for himself, Mr. Harkin, Mr. Dodd, and Mr. Kennedy) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

# A BILL

To prohibit health insurance and employment discrimination against individuals and their family members on the basis of predictive genetic information or genetic services.

- 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 Act
- 6 of 1999".

1	TITLE I—PROHIBITION OF
2	HEALTH INSURANCE DIS-
3	CRIMINATION ON THE BASIS
4	OF PREDICTIVE 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 PRE-
10	DICTIVE 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 PREDICTIVE 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 PREDICTIVE 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 predictive 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-

- formation about a request or receipt of genetic services by an individual or family
  member of such individual), (c), (d), (e),
  (f), or (g) of section 702, section 711 and
  section 714".
- 6 (b) Limitations on Genetic Testing and on 7 Collection and Disclosure of Predictive 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.—

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- "(1) Limitation on requesting or requireing genetic testing.—A group health plan, or a
  health insurance issuer offering health insurance
  coverage in connection with a group health plan,
  shall not request or require an individual or a family
  member of such individual to undergo a genetic test.
  - "(2) Rule of construction.—Nothing in this title shall be construed to limit the authority of a health care professional, who is providing treatment with respect to an individual and who is employed by a group health plan or a health insurance issuer, to request that such individual or family member of such individual undergo a genetic test. 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 Predictive Genetic Infor-MATION.—Except as provided in subsections (f) and (g), 5 a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request, require, collect, or purchase 8 predictive genetic information concerning an individual (or 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 Predictive Genetic Infor-MATION.—A group health plan, or a health insurance issuer offering health insurance coverage in connection 14 with a group health plan, shall not disclose predictive genetic 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 predictive genetic infor-
12	mation 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	predictive 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

- individual if the individual (or legal representative of the individual) provides prior, knowing, voluntary,
- and written authorization for the collection or disclo-
- 4 sure of predictive genetic information.
- 5 "(2) DISCLOSURE FOR HEALTH CARE TREAT6 MENT.—Nothing in this section shall be construed to
  7 limit or restrict the disclosure of predictive genetic
  8 information from a health care provider to another
  9 health care provider for the purpose of providing

health care treatment to the individual involved.

11 "(i) Definitions.—In this section:

- "(1) CONTROLLED GROUP.—The term 'controlled group' means any group treated as a single employer under subsections (b), (c), (m), or (o)of 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)) shall apply for purposes of the Secretary en-
- 16 forcing the provisions referred to in subsection (n), except
- 17 that any such relief awarded shall be paid only into the
- 18 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)"
- after "subsection (b)"; and
- 24 (2) by adding at the end the following:

"(e) Special Rule in Case of Genetic Informa-1 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 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 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

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; and
5	"(C) all other individuals related by blood
6	to the individual or 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.—The term 'genetic test'
21	means the analysis of human DNA, RNA, chro-
22	mosomes, proteins, and certain metabolites in order
23	to detect genotypes, mutations, or chromosomal
24	changes.
25	"(9) Predictive genetic information.—

1	"(A) In General.—The term 'predictive
2	genetic information' means—
3	"(i) information about an individual's
4	genetic tests;
5	"(ii) information about genetic tests
6	of family members of the individual; or
7	"(iii) information about the occur-
8	rence of a disease or disorder in family
9	members.
10	"(B) Limitations.—The term 'predictive
11	genetic information' shall not include—
12	"(i) information about the sex or age
13	of the individual;
14	"(ii) information about chemical,
15	blood, or urine analyses of the individual,
16	unless these analyses are genetic tests; or
17	"(iii) information about physical
18	exams of the individual, and other informa-
19	tion relevant to determining the current
20	health status of the individual.".
21	(f) Amendment Concerning Supplemental Ex-
22	CEPTED BENEFITS.—Section 732(c)(3) of the Employee
23	Retirement Income Security Act of 1974 (29 U.S.C.
24	1191a(c)(3)) is amended by inserting ", other than the
25	requirements of subsections (a)(1)(F), (b) (in cases relat-

- 1 ing to genetic information or information about a request
- 2 for or the receipt of genetic services by an individual or
- 3 a family member of such individual), (c), (d), (e), (f) and
- 4 (g) of section 702 and section 714," after "The require-
- 5 ments of this part".
- 6 (g) Effective Date.—
- 7 (1) In General.—Except as provided in this 8 section, this section and the amendments made by 9 this section shall apply with respect to group health 10 plans for plan years beginning after October 1, 11 2000.
- 12 (2)SPECIAL RULE FOR COLLECTIVE 13 GAINING AGREEMENTS.—In the case of a group 14 health plan maintained pursuant to one or more col-15 lective bargaining agreements between employee rep-16 resentatives and one or more employers ratified be-17 fore the date of the enactment of this Act, this sec-18 tion and the amendments made by this section shall 19 not apply to plan years beginning before the later 20 of—
- 21 (A) the date on which the last of the col-22 lective bargaining agreements relating to the 23 plan terminates (determined without regard to 24 any extension thereof agreed to after the date 25 of the enactment of this Act), or

1	(B) October 1, 2000.
2	For purposes of subparagraph (A), any plan amend-
3	ment made pursuant to a collective bargaining
4	agreement relating to the plan which amends the
5	plan solely to conform to any requirement of the
6	amendments made by this section shall not be treat-
7	ed as a termination of such collective bargaining
8	agreement.
9	SEC. 102. AMENDMENTS TO THE PUBLIC HEALTH SERVICE
10	ACT.
11	(a) Amendments Relating to the Group Mar-
12	KET.—
13	(1) Prohibition of Health insurance dis-
14	CRIMINATION ON THE BASIS OF PREDICTIVE GE-
15	NETIC INFORMATION OR GENETIC SERVICES.—
16	(A) No enrollment restriction for
17	GENETIC SERVICES.—Section 2702(a)(1)(F) of
18	the Public Health Service Act (42 U.S.C.
19	300gg-1(a)(1)(F)) is amended by inserting be-
20	fore the period the following: "(or information
21	about a request for or the receipt of genetic
22	services by an individual or a family member of
23	such individual)".

1	(B) No discrimination in group rate
2	BASED ON PREDICTIVE GENETIC INFORMA-
3	TION.—
4	(i) In general.—Subpart 2 of part
5	A of title XXVII of the Public Health
6	Service (42 U.S.C. 300gg-4 et seq.) is
7	amended by adding at the end the fol-
8	lowing:
9	"SEC. 2707. PROHIBITING DISCRIMINATION AGAINST
10	GROUPS ON THE BASIS OF PREDICTIVE GE-
11	NETIC INFORMATION.
12	"A group health plan, and a health insurance issuer
13	offering group health insurance coverage in connection
14	with a group health plan, shall not deny eligibility to a
15	group or adjust premium or contribution rates for a group
16	on the basis of predictive genetic information concerning
17	an individual in the group (or information about a request
18	for or the receipt of genetic services by such individual
19	or family member of such individual).".
20	(ii) Conforming amendments.—
21	(I) Section $2702(b)(2)(A)$ of the
22	Public Health Service Act (42 U.S.C.
23	300gg-1(b)(2)(A)) is amended to read
24	as follows:

1	"(A) to restrict the amount that an em-
2	ployer may be charged for coverage under a
3	group health plan, except as provided in section
4	2707; or''.
5	(II) Section 2721(a) of the Pub-
6	lic Health Service Act (42 U.S.C.
7	300gg-21(a)) is amended by inserting
8	"(other than subsections $(a)(1)(F)$ ,
9	(b) (with respect to cases relating to
10	genetic information or information
11	about a request or receipt of genetic
12	services by an individual or family
13	member of such individual), (c), (d),
14	(e), (f), or (g) of section 2702 and
15	section 2707)" after "subparts 1 and
16	3".
17	(2) Limitations on genetic testing and on
18	COLLECTION AND DISCLOSURE OF PREDICTIVE GE-
19	NETIC INFORMATION.—Section 2702 of the Public
20	Health Service Act (42 U.S.C. 300gg-1) is amended
21	by adding at the end the following:
22	"(c) Genetic Testing.—
23	"(1) Limitation on requesting or requir-
24	ING GENETIC TESTING.—A group health plan, or a
25	health insurance issuer offering health insurance

- 1 coverage in connection with a group health plan, 2 shall not request or require an individual or a family
- member of such individual to undergo a genetic test.
- 4 "(2) Rule of Construction.—Nothing in
- 5 this title shall be construed to limit the authority of
- 6 a health care professional, who is providing treat-
- 7 ment with respect to an individual and who is em-
- 8 ployed by a group health plan or a health insurance
- 9 issuer, to request that such individual or family
- member of such individual undergo a genetic test.
- 11 Such a health care professional shall not require
- that such individual or family member undergo a ge-
- netic test.
- 14 "(d) Collection of Predictive Genetic Infor-
- 15 MATION.—Except as provided in subsections (f) and (g),
- 16 a group health plan, or a health insurance issuer offering
- 17 health insurance coverage in connection with a group
- 18 health plan, shall not request, require, collect, or purchase
- 19 predictive genetic information concerning an individual (or
- 20 information about a request for or the receipt of genetic
- 21 services by such individual or family member of such indi-
- 22 vidual).
- 23 "(e) Disclosure of Predictive Genetic Infor-
- 24 MATION.—A group health plan, or a health insurance
- 25 issuer offering health insurance coverage in connection

1	with a group health plan, shall not disclose predictive ge-
2	netic information about an individual (or information
3	about a request for or the receipt of genetic services by
4	such individual or family member of such individual) to—
5	"(1) any entity that is a member of the same
6	controlled group as such issuer or plan sponsor of
7	such group health plan;
8	"(2) any other group health plan or health in-
9	surance issuer or any insurance agent, third party
10	administrator, or other person subject to regulation
11	under State insurance laws;
12	"(3) the Medical Information Bureau or any
13	other person that collects, compiles, publishes, or
14	otherwise disseminates insurance information;
15	"(4) the individual's employer or any plan spon-
16	sor; or
17	"(5) any other person the Secretary may speci-
18	fy in regulations.
19	"(f) Information for Payment for Genetic
20	Services.—
21	"(1) In general.—With respect to payment
22	for genetic services conducted concerning an indi-
23	vidual or the coordination of benefits, a group health
24	plan, or a health insurance issuer offering group

health insurance coverage in connection with a group

1	health plan, may request that the individual provide
2	the plan or issuer with evidence that such services
3	were performed.
4	"(2) Rule of Construction.—Nothing in
5	paragraph (1) shall be construed to—
6	"(A) permit a group health plan or health
7	insurance issuer to request (or require) the re-
8	sults of the services referred to in such para-
9	graph; or
10	"(B) require that a group health plan or
11	health insurance issuer make payment for serv-
12	ices described in such paragraph where the in-
13	dividual involved has refused to provide evi-
14	dence of the performance of such services pur-
15	suant to a request by the plan or issuer in ac-
16	cordance with such paragraph.
17	"(g) Information for Payment of Other
18	CLAIMS.—With respect to the payment of claims for bene-
19	fits other than genetic services, a group health plan, or
20	a health insurance issuer offering group health insurance
21	coverage in connection with a group health plan, may re-
22	quest that an individual provide predictive genetic infor-
23	mation so long as such information—
24	"(1) is used solely for the payment of a claim;

"(2) is limited to information that is directly related to and necessary for the payment of such claim and the claim would otherwise be denied but for the predictive genetic information; and

> "(3) is used only by an individual (or individuals) within such plan or issuer who needs access to such information for purposes of payment of a claim.

#### "(h) Rules of Construction.—

- "(1) Collection or disclosure authorized By individual.—The provisions of subsections (d) (regarding collection) and (e) shall not apply to an individual if the individual (or legal representative of the individual) provides prior, knowing, voluntary, and written authorization for the collection or disclosure of predictive genetic information.
- "(2) DISCLOSURE FOR HEALTH CARE TREAT-MENT.—Nothing in this section shall be construed to limit or restrict the disclosure of predictive genetic information from a health care provider to another health care provider for the purpose of providing health care treatment to the individual involved.

### 23 "(i) Definitions.—In this section:

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

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1	employer under subsections (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	(3) Definitions.—Section 2791(d) of the Pub-
9	lic Health Service Act (42 U.S.C. 300gg-91(d)) is
10	amended by adding at the end the following new
11	paragraphs:
12	"(15) Family Member.—The term 'family
13	member' means with respect to an individual—
14	"(A) the spouse of the individual;
15	"(B) a dependent child of the individual,
16	including a child who is born to or placed for
17	adoption with the individual; and
18	"(C) all other individuals related by blood
19	to the individual or the spouse or child de-
20	scribed in subparagraph (A) or (B).
21	"(16) Genetic information.—The term 'ge-
22	netic information' means information about genes,
23	gene products, or inherited characteristics that may
24	derive from an individual or a family member of
25	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	"(17) 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 counselling.
8	"(18) Genetic test.—The term 'genetic test'
9	means the analysis of human DNA, RNA, chro-
10	mosomes, proteins, and certain metabolites in order
11	to detect genotypes, mutations, or chromosomal
12	changes.
13	"(19) Predictive genetic information.—
14	"(A) IN GENERAL.—The term 'predictive
15	genetic information' 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	"(B) Limitations.—The term 'predictive
24	genetic information' shall not include—

1	"(i) information about the sex or age
2	of the individual;
3	"(ii) information about chemical,
4	blood, or urine analyses of the individual,
5	unless these analyses are genetic tests; or
6	"(iii) information about physical
7	exams of the individual, and other informa-
8	tion relevant to determining the current
9	health status of the individual.".
10	(b) Amendment Relating to the Individual
11	Market.—The first subpart 3 of part B of title XXVII
12	of the Public Health Service Act (42 U.S.C. 300gg–51 et
13	seq.) is amended—
14	(1) by redesignating such subpart as subpart 2;
15	and
16	(2) by adding at the end the following:
17	"SEC. 2753. PROHIBITION OF HEALTH INSURANCE DIS-
18	CRIMINATION AGAINST INDIVIDUALS ON THE
19	BASIS OF PREDICTIVE GENETIC INFORMA-
20	TION.
21	"(a) In Eligibility To Enroll.—A health insur-
22	ance issuer offering health insurance coverage in the indi-
23	vidual market shall not establish rules for eligibility to en-
24	roll in individual health insurance coverage that are based
25	on predictive genetic information concerning the individual

- 1 (or information about a request for or the receipt of ge-
- 2 netic services by such individual or family member of such
- 3 individual).
- 4 "(b) IN Premium Rates.—A health insurance issuer
- 5 offering health insurance coverage in the individual mar-
- 6 ket shall not adjust premium rates on the basis of pre-
- 7 dictive genetic information concerning an individual (or in-
- 8 formation about a request for or the receipt of genetic
- 9 services by such individual or family member of such indi-
- 10 vidual).
- 11 "SEC. 2754. LIMITATIONS ON GENETIC TESTING AND ON
- 12 COLLECTION AND DISCLOSURE OF PRE-
- 13 DICTIVE GENETIC INFORMATION.
- 14 "(a) Genetic Testing.—
- 15 "(1) Limitation on requesting or requir-
- 16 ING GENETIC TESTING.—A health insurance issuer
- offering health insurance coverage in the individual
- market shall not request or require an individual or
- a family member of such individual to undergo a ge-
- 20 netic test.
- 21 "(2) Rule of Construction.—Nothing in
- this title shall be construed to limit the authority of
- a health care professional, who is providing treat-
- 24 ment with respect to an individual and who is em-
- 25 ployed by a group health plan or a health insurance

- 1 issuer, to request that such individual or family
- 2 member of such individual undergo a genetic test.
- 3 Such a health care professional shall not require
- 4 that such individual or family member undergo a ge-
- 5 netic test.
- 6 "(b) Collection of Predictive Genetic Infor-
- 7 MATION.—Except as provided in subsections (d) and (e),
- 8 a health insurance issuer offering health insurance cov-
- 9 erage in the individual market shall not request, require,
- 10 collect, or purchase predictive genetic information con-
- 11 cerning an individual (or information about a request for
- 12 or the receipt of genetic services by such individual or fam-
- 13 ily member of such individual).
- 14 "(c) Disclosure of Predictive Genetic Infor-
- 15 MATION.—A health insurance issuer offering health insur-
- 16 ance coverage in the individual market shall not disclose
- 17 predictive genetic information about an individual (or in-
- 18 formation about a request for or the receipt of genetic
- 19 services by such individual or family member of such indi-
- 20 vidual) to—
- 21 "(1) any entity that is a member of the same
- controlled group as such issuer or plan sponsor of
- such group health plan;
- 24 "(2) any other group health plan or health in-
- 25 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	"(d) 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 health insur-
15	ance issuer offering health insurance coverage in the
16	individual market may request that the individual
17	provide the plan or issuer with evidence that such
18	services were performed.
19	"(2) Rule of construction.—Nothing in
20	paragraph (1) shall be construed to—
21	"(A) permit a health insurance issuer to
22	request (or require) the results of the services
23	referred to in such paragraph; or
24	"(B) require that a health insurance issuer
25	make nayment for services described in such

1	paragraph where the individual involved has re-
2	fused to provide evidence of the performance of
3	such services pursuant to a request by the plan
4	or issuer in accordance with such paragraph.
5	"(e) Information for Payment of Other
6	CLAIMS.—With respect to the payment of claims for bene-
7	fits other than genetic services, a health insurance issuer
8	offering health insurance coverage in the individual mar-
9	ket may request that an individual provide predictive ge-
10	netic information so long as such information—
11	"(1) is used solely for the payment of a claim;
12	"(2) is limited to information that is directly re-
13	lated to and necessary for the payment of such claim
14	and the claim would otherwise be denied but for the
15	predictive genetic information; and
16	"(3) is used only by an individual (or individ-
17	uals) within such plan or issuer who needs access to
18	such information for purposes of payment of a
19	claim.
20	"(f) Rules of Construction.—
21	"(1) Collection or disclosure authorized
22	BY INDIVIDUAL.—The provisions of subsections (c)
23	(regarding collection) and (d) shall not apply to an
24	individual if the individual (or legal representative of
25	the individual) provides prior, knowing, voluntary,

- and written authorization for the collection or disclosure of predictive genetic information.
- "(2) DISCLOSURE FOR HEALTH CARE TREATMENT.—Nothing in this section shall be construed to
  limit or restrict the disclosure of predictive genetic
  information from a health care provider to another
  health care provider for the purpose of providing
  health care treatment to the individual involved.
- 9 "(g) Definitions.—In this section:

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- "(1) CONTROLLED GROUP.—The term 'controlled group' means any group treated as a single employer under subsections (b), (c), (m), or (o) of section 414 of the Internal Revenue Code of 1986.
- "(2) Group Health Plan, Health Insur-Ance Issuer.—The terms 'group health plan' and 'health insurance issuer' include a third party administrator or other person acting for or on behalf of such plan or issuer.".

#### (c) Enforcement.—

- 20 (1) Group Plans.—Section 2722 of the Public 21 Health Service Act (42 U.S.C. 300gg-22) is amend-22 ed by adding at the end the following:
- 23 "(c) Violation of Genetic Discrimination or24 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 subsections (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 2702 and section 2707 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 "(d) Civil Penalty.—The monetary provisions of
- 14 section 308(b)(2)(C) of Public Law 101–336 (42 U.S.C.
- 15 12188(b)) shall apply for purposes of the Secretary en-
- 16 forcing the provisions referred to in subsection (c), except
- 17 that any such relief awarded shall be paid only into the
- 18 general fund of the Treasury.".
- 19 (2) Individual Plans.—Section 2761 of the
- 20 Public Health Service Act (42 U.S.C. 300gg-45) is
- amended by adding at the end the following:
- 22 "(c) Violation of Genetic Discrimination or
- 23 Genetic Disclosure Provisions.—In any action under
- 24 this section against any health insurance issuer offering
- 25 health insurance coverage in the individual market (in-

- 1 cluding any other person acting for or on behalf of such
- 2 issuer) alleging a violation of section 2753 and 2754 the
- 3 court in which the action is commenced may award any
- 4 appropriate legal or equitable relief. Such relief may in-
- 5 clude a requirement for the payment of attorney's fees and
- 6 costs, including the costs of expert witnesses.
- 7 "(d) Civil Penalty.—The monetary provisions of
- 8 section 308(b)(2)(C) of Public Law 101–336 (42 U.S.C.
- 9 12188(b)) shall apply for purposes of the Secretary en-
- 10 forcing the provisions referred to in subsection (c), except
- 11 that any such relief awarded shall be paid only into the
- 12 general fund of the Treasury.".
- 13 (d) Preemption.—
- 14 (1) Group Market.—Section 2723 of the Pub-
- lic Health Service Act (42 U.S.C. 300gg–23) is
- 16 amended—
- (A) in subsection (a)(1), by inserting "or
- (e)" after "subsection (b)"; and
- 19 (B) by adding at the end the following:
- 20 "(e) Special Rule in Case of Genetic Informa-
- 21 TION.—With respect to group health insurance coverage
- 22 offered by a health insurance issuer, the provisions of this
- 23 part relating to genetic information (including information
- 24 about a request for or the receipt of genetic services by
- 25 an individual or a family member of such individual) shall

1	not be construed to supersede any provision of State law
2	which establishes, implements, or continues in effect a
3	standard, requirement, or remedy that more completely—
4	"(1) protects the confidentiality of genetic in-
5	formation (including information about a request for
6	or the receipt of genetic services by an individual or
7	a family member of such individual) or the privacy
8	of an individual or a family member of the individual
9	with respect to genetic information (including infor-
10	mation about a request for or the receipt of genetic
11	services by an individual or a family member of such
12	individual); or
13	"(2) prohibits discrimination on the basis of ge-
14	netic information than does this part.".
15	(2) Individual Market.—Section 2762 of the
16	Public Health Service Act (42 U.S.C. 300gg-46) is
17	amended—
18	(A) in subsection (a), by inserting "and ex-
19	cept as provided in subsection (c)," after "Sub-
20	ject to subsection (b),"; and
21	(B) by adding at the end the following:
22	"(c) Special Rule in Case of Genetic Informa-
23	TION.—With respect to individual health insurance cov-
24	erage offered by a health insurance issuer, the provisions
25	of this part (or part C insofar as it applies to this part)

- 1 relating to genetic information (including information
- 2 about a request for or the receipt of genetic services by
- 3 an individual or a family member of such individual) shall
- 4 not be construed to supersede any provision of State law
- 5 (as defined in section 2723(d)) which establishes, imple-
- 6 ments, or continues in effect a standard, requirement, or
- 7 remedy that more completely—
- 8 "(1) protects the confidentiality of genetic in-
- 9 formation (including information about a request for
- or the receipt of genetic services of an individual or
- a family member of such individual) or the privacy
- of an individual or a family member of the individual
- with respect to genetic information (including infor-
- mation about a request for or the receipt of genetic
- services by an individual or a family member of such
- individual) than does this part (or part C insofar as
- it applies to this part); or
- 18 "(2) prohibits discrimination on the basis of ge-
- netic information than does this part (or part C in-
- sofar as it applies to this part).".
- 21 (e) Elimination of Option of Non-Federal
- 22 GOVERNMENTAL PLANS TO BE EXCEPTED FROM RE-
- 23 QUIREMENTS CONCERNING GENETIC INFORMATION.—
- 24 Section 2721(b)(2) of the Public Health Service Act (42
- 25 U.S. C. 300gg–21(b)(2)) is amended—

1	(1) in subparagraph (A), by striking "If the
2	plan sponsor" and inserting "Except as provided in
3	subparagraph (D), if the plan sponsor'; and
4	(2) by adding at the end the following:
5	"(D) ELECTION NOT APPLICABLE TO RE-
6	QUIREMENTS CONCERNING GENETIC INFORMA-
7	TION.—The election described in subparagraph
8	(A) shall not be available with respect to the
9	provisions of subsections (a)(1)(F), (c), (d), (e),
10	(f), and (g) of section 2702 and section 2707,
11	and the provisions of section 2702(b) to the ex-
12	tent that they apply to genetic information (or
13	information about a request for or the receipt
14	of genetic services by an individual or a family
15	member of such individual).".
16	(f) Amendment Concerning Supplemental Ex-
17	CEPTED BENEFITS.—
18	(1) Group Market.—Section 2721(d)(3) of
19	the Public Health Service Act (42 U.S.C. 300gg-
20	23(d)(3)) is amended by inserting ", other than the
21	requirements of subsections (a)(1)(F), (b) (in cases
22	relating to genetic information or information about
23	a request for or the receipt of genetic services by an

individual or a family member of such individual)),

1	(e), (d), (e), (f) and (g) of section 2702 and section
2	2707," after "The requirements of this part".
3	(2) Individual market.—Section 2763(b) of
4	the Public Health Service Act (42 U.S.C. 300gg-
5	47(b)) is amended—
6	(A) by striking "The requirements of this
7	part" and inserting the following:
8	"(1) In general.—Except as provided in para-
9	graph (2), the requirements of this part"; and
10	(B) by adding at the end the following:
11	"(2) Limitation.—The requirements of sec-
12	tions 2753 and 2754 shall apply to excepted benefits
13	described in section 2791(c)(4).".
14	(g) Effective Date.—
15	(1) IN GENERAL.—The amendments made by
16	this section shall apply with respect to—
17	(A) group health plans, and health insur-
18	ance coverage offered in connection with group
19	health plans, for plan years beginning; and
20	(B) health insurance coverage offered,
21	sold, issued, renewed, in effect, or operated in
22	the individual market, after;
23	October 1, 2000.
24	(2) Special rule for collective bar-
25	GAINING AGREEMENTS —In the case of a group

1	health plan maintained pursuant to one or more col-
2	lective bargaining agreements between employee rep
3	resentatives and one or more employers ratified be-
4	fore the date of the enactment of this Act, the
5	amendments made by this section shall not apply to
6	plan years beginning before the later of—
7	(A) the date on which the last of the col-
8	lective bargaining agreements relating to the
9	plan terminates (determined without regard to
10	any extension thereof agreed to after the date
11	of the enactment of this Act); or
12	(B) October 1, 2000.
13	For purposes of subparagraph (A), any plan amend-
14	ment made pursuant to a collective bargaining
15	agreement relating to the plan which amends the
16	plan solely to conform to any requirement of the
17	amendments made by this section shall not be treat
18	ed as a termination of such collective bargaining
19	agreement.
20	SEC. 103. AMENDMENTS TO INTERNAL REVENUE CODE OF
21	1986.
22	(a) Prohibition of Health Insurance Discrimi-
23	NATION ON THE BASIS OF GENETIC SERVICES OR PRE-
24	DICTIVE GENETIC INFORMATION.—

1	(1) No enrollment restriction for ge-
2	NETIC SERVICES.—Section 9802(a)(1)(F) of the In-
3	ternal Revenue Code of 1986 is amended by insert-
4	ing before the period "(or information about a re-
5	quest for or the receipt of genetic services by such
6	individual or family member of such individual)".
7	(2) No discrimination in group rate based
8	ON PREDICTIVE GENETIC INFORMATION.—
9	(A) In general.—Subchapter B of chap-
10	ter 100 of the Internal Revenue Code of 1986
11	is amended by adding at the end the following:
12	"SEC. 9813. PROHIBITING DISCRIMINATION AGAINST
13	GROUPS ON THE BASIS OF PREDICTIVE GE-
	GROUPS ON THE BASIS OF PREDICTIVE GENETIC INFORMATION.
13	
13 14 15	NETIC INFORMATION.
13 14 15	NETIC INFORMATION.  "A group health plan shall not deny eligibility to a
13 14 15 16 17	NETIC INFORMATION.  "A group health plan shall not deny eligibility to a group or adjust premium or contribution rates for a group
13 14 15 16 17	NETIC INFORMATION.  "A group health plan shall not deny eligibility to a group or adjust premium or contribution rates for a group on the basis of predictive genetic information concerning
13 14 15 16 17	NETIC INFORMATION.  "A group health plan shall not deny eligibility to a group or adjust premium or contribution rates for a group on the basis of predictive genetic information concerning an individual in the group (or information about a request
13 14 15 16 17 18	NETIC INFORMATION.  "A group health plan shall not deny eligibility to a group or adjust premium or contribution rates for a group on the basis of predictive genetic information concerning an individual in the group (or information about a request for or the receipt of genetic services by such individual
13 14 15 16 17 18 19 20	NETIC INFORMATION.  "A group health plan shall not deny eligibility to a group or adjust premium or contribution rates for a group on the basis of predictive genetic information concerning an individual in the group (or information about a request for or the receipt of genetic services by such individual or family member of such individual)."
13 14 15 16 17 18 19 20 21	"A group health plan shall not deny eligibility to a group or adjust premium or contribution rates for a group on the basis of predictive genetic information concerning an individual in the group (or information about a request for or the receipt of genetic services by such individual or family member of such individual)."  (B) Conforming amendments.—

1	"(A) to restrict the amount that an em-
2	ployer may be charged for coverage under a
3	group health plan, except as provided in section
4	9813; or".
5	(ii) Section 9831(a) of the Internal
6	Revenue Code of 1986 is amended by in-
7	serting "(other than subsections $(a)(1)(F)$ ,
8	(b) (with respect to cases relating to ge-
9	netic information or information about a
10	request for or receipt of genetic services by
11	an individual or family member of such in-
12	dividual), (d) (e), (f), (g) or (h) of section
13	9802 or section 9813) after "chapter".
14	(b) Limitations on Genetic Testing and on
15	COLLECTION AND DISCLOSURE OF PREDICTIVE GENETIC
16	Information.—Section 9802 of the Internal Revenue
17	Code of 1986 is amended by adding at the end the fol-
18	lowing:
19	"(d) Genetic Testing.—
20	"(1) Limitation on requesting or requir-
21	ING GENETIC TESTING.—A group health plan shall
22	not request or require an individual or a family
23	member of such individual to undergo a genetic test.
24	"(2) Rule of Construction.—Nothing in
25	this title shall be construed to limit the authority of

- a health care professional, who is providing treatment with respect to an individual and who is em-
- = inone with respect to the intervious that will be
- 3 ployed by a group health plan, to request that such
- 4 individual or family member of such individual un-
- 5 dergo a genetic test. Such a health care professional
- 6 shall not require that such individual or family mem-
- 7 ber undergo a genetic test.
- 8 "(e) Collection of Predictive Genetic Infor-
- 9 MATION.—Except as provided in subsections (g) and (h),
- 10 a group health plan shall not request, require, collect, or
- 11 purchase predictive genetic information concerning an in-
- 12 dividual (or information about a request for or the receipt
- 13 of genetic services by such individual or family member
- 14 of such individual).
- 15 "(f) Disclosure of Predictive Genetic Infor-
- 16 MATION.—A group health plan shall not disclose predictive
- 17 genetic 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
- such group health plan;
- 23 "(2) any other group health plan or health in-
- 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	"(g) 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 may request that the individual provide the
16	plan with evidence that such services were per-
17	formed.
18	"(2) Rule of Construction.—Nothing in
19	paragraph (1) shall be construed to—
20	"(A) permit a group health plan to request
21	(or require) the results of the services referred
22	to in such paragraph; or
23	"(B) require that a group health plan
24	make payment for services described in such
25	paragraph where the individual involved has re-

1	fused to provide evidence of the performance of
2	such services pursuant to a request by the plan
3	in accordance with such paragraph.
4	"(h) Information for Payment of Other
5	CLAIMS.—With respect to the payment of claims for bene-
6	fits other than genetic services, a group health plan may
7	request that an individual provide predictive genetic infor-
8	mation so long as such information—
9	"(1) is used solely for the payment of a claim;
10	"(2) is limited to information that is directly re-
11	lated to and necessary for the payment of such claim
12	and the claim would otherwise be denied but for the
13	predictive genetic information; and
14	"(3) is used only by an individual (or individ-
15	uals) within such plan or issuer who needs access to
16	such information for purposes of payment of a
17	claim.
18	"(i) Rules of Construction.—
19	"(1) Collection or disclosure authorized
20	BY INDIVIDUAL.—The provisions of subsections (e)
21	(regarding collection) and (f) shall not apply to an
22	individual if the individual (or legal representative of
23	the individual) provides prior, knowing, voluntary,
24	and written authorization for the collection or disclo-

sure of predictive genetic information.

- 1 "(2) DISCLOSURE FOR HEALTH CARE TREAT2 MENT.—Nothing in this section shall be construed to
  3 limit or restrict the disclosure of predictive genetic
  4 information from a health care provider to another
  5 health care provider for the purpose of providing
  6 health care treatment to the individual involved.
- 7 "(j) Definitions.—In this section:
- 8 "(1) CONTROLLED GROUP.—The term 'con-9 trolled group' means any group treated as a single 10 employer under subsections (b), (c), (m), or (o) of 11 section 414.
- "(2) GROUP HEALTH PLAN, HEALTH INSURANCE ISSUER.—The terms 'group health plan' and
  'health insurance issuer' include a third party administrator or other person acting for or on behalf
  of such plan or issuer.
- "(k) VIOLATION OF GENETIC DISCRIMINATION OR

  18 GENETIC DISCLOSURE PROVISIONS.—In any action under

  19 this section against any administrator of a group health

  20 plan (including any third party administrator or other per
  21 son acting for or on behalf of such plan) alleging a viola
  22 tion of subsection (a)(1)(F), (b) (with respect to cases re
  23 lating to genetic information or information about a re
  24 quest or receipt of genetic services by an individual or fam-

ily member of such individual), (d), (e), (f), (g) or (h) of

this section or section 9813, the court may award any appropriate legal or equitable relief. Such relief may include 3 a requirement for the payment of attorney's fees and 4 costs, including the costs of expert witnesses. 5 "(1) CIVIL PENALTY.—The monetary provisions of section 308(b)(2)(C) of Public Law 101–336 (42 U.S.C. 6 12188(b)) shall apply for purposes of the Secretary en-8 forcing the provisions referred to in subsection (k), except that any such relief awarded shall be paid only into the 10 general fund of the Treasury.". 11 (c) Definitions.—Section 9832(d) of the Internal 12 Revenue Code of 1986 is amended by adding at the end the following: 13 14 Family Member.—The term 'family 15 member' means with respect to an individual— "(A) the spouse of the individual; 16 "(B) a dependent child of the individual, 17 18 including a child who is born to or placed for 19 adoption with the individual; and 20 "(C) all other individuals related by blood 21 to the individual or the spouse or child de-22 scribed in subparagraph (A) or (B). 23 "(7) GENETIC INFORMATION.—The term 'ge-24 netic information' means information about genes,

gene products, or inherited characteristics that may

1	derive from an individual or a family member of
2	such individual (including information about a re-
3	quest for or the receipt of genetic services by such
4	individual or family member of such individual).
5	"(8) Genetic services.—The term 'genetic
6	services' means health services, including genetic
7	tests, provided to obtain, assess, or interpret genetic
8	information for diagnostic and therapeutic purposes,
9	and for genetic education and counseling.
10	"(9) Genetic test.—The term 'genetic test'
11	means the analysis of human DNA, RNA, chro-
12	mosomes, proteins, and certain metabolites in order
13	to detect genotypes, mutations, or chromosomal
14	changes.
15	"(10) Predictive genetic information.—
16	"(A) In General.—The term 'predictive
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 'predictive
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 relevant to determining the current
11	health status of the individual.".
12	(d) Effective Date.—
13	(1) In general.—Except as provided in this
14	section, this section and the amendments made by
15	this section shall apply with respect to group health
16	plans for plan years beginning after October 1,
17	2000.
18	(2) Special rule for collective bar-
19	GAINING AGREEMENTS.—In the case of a group
20	health plan maintained pursuant to one or more col-
21	lective bargaining agreements between employee rep-
22	resentatives and one or more employers ratified be-
23	fore the date of the enactment of this Act, this sec-

tion and the amendments made by this section shall

1	not apply to plan years beginning before the later
2	of—
3	(A) the date on which the last of the col-
4	lective bargaining agreements relating to the
5	plan terminates (determined without regard to
6	any extension thereof agreed to after the date
7	of the enactment of this Act), or
8	(B) October 1, 2000.
9	For purposes of subparagraph (A), any plan amend-
10	ment made pursuant to a collective bargaining
11	agreement relating to the plan which amends the
12	plan solely to conform to any requirement of the
13	amendments made by this section shall not be treat-
14	ed as a termination of such collective bargaining
15	agreement.
16	SEC. 104. AMENDMENTS TO TITLE XVIII OF THE SOCIAL SE-
17	CURITY ACT RELATING TO MEDIGAP.
18	(a) Nondiscrimination.—
19	(1) In General.—Section 1882(s)(2) of the
20	Social Security Act (42 U.S.C. 1395ss(s)(2)) is
21	amended by adding at the end the following:
22	"(E)(i) An issuer of a medicare supple-
23	mental policy shall not deny or condition the
24	issuance or effectiveness of the policy, and shall
25	not discriminate in the pricing of the policy (in-

1	cluding the adjustment of premium rates) of an
2	eligible individual on the basis of predictive ge-
3	netic information concerning the individual (or
4	information about a request for, or the receipt
5	of, genetic services by such individual or family
6	member of such individual).
7	"(ii) For purposes of clause (i), the terms
8	'family member', 'genetic services', and 'pre-
9	dictive genetic information' shall have the
10	meanings given such terms in subsection (v).".
11	(2) Effective date.—The amendment made
12	by paragraph (1) shall apply with respect to a policy
13	for policy years beginning after October 1, 2000.
14	(b) Limitations on Genetic Testing and on
15	COLLECTION AND DISCLOSURE OF PREDICTIVE GENETIC
16	Information.—
17	(1) In General.—Section 1882 of the Social
18	Security Act (42 U.S.C. 1395ss) is amended by add-
19	ing at the end the following:
20	"(v) Limitations on Genetic Testing and on
21	COLLECTION AND DISCLOSURE OF PREDICTIVE GENETIC
22	Information.—
23	"(1) Genetic testing.—
24	"(A) Limitation on requesting or re-
25	QUIRING GENETIC TESTING.—An issuer of a

1 medicare supplemental policy shall not request 2 or require an individual or a family member of 3 such individual to undergo a genetic test.

"(B) RULE OF CONSTRUCTION.—Nothing in this title shall be construed to limit the authority of a health care professional, who is providing treatment with respect to an individual and who is employed by an issuer of a medicare supplemental policy, to request that such individual or family member of such individual undergo a genetic test. Such a health care professional shall not require that such individual or family member undergo a genetic test.

"(2) Collection of predictive genetic information.—Except as provided in paragraphs (4) and (5), an issuer of a medicare supplemental policy shall not request, require, collect, or purchase predictive genetic information concerning an individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual).

"(3) DISCLOSURE OF PREDICTIVE GENETIC IN-FORMATION.—An issuer of a medicare supplemental policy shall not disclose predictive genetic information about an individual (or information about a re-

1	quest for or the receipt of genetic services by such
2	individual or family member of such individual) to—
3	"(A) any entity that is a member of the
4	same controlled group as such issuer;
5	"(B) any issuer of a medicare supple-
6	mental policy, group health plan or health in-
7	surance issuer, or any insurance agent, third
8	party administrator, or other person subject to
9	regulation under State insurance laws;
10	"(C) the Medical Information Bureau or
11	any other person that collects, compiles, pub-
12	lishes, or otherwise disseminates insurance in-
13	formation;
14	"(D) the individual's employer or any plan
15	sponsor; or
16	"(E) any other person the Secretary may
17	specify in regulations.
18	"(4) Information for payment for ge-
19	NETIC SERVICES.—
20	"(A) IN GENERAL.—With respect to pay-
21	ment for genetic services conducted concerning
22	an individual or the coordination of benefits, an
23	issuer of a medicare supplemental policy may
24	request that the individual provide the issuer

1	with evidence that such services were per-
2	formed.
3	"(B) Rule of Construction.—Nothing
4	in subparagraph (A) shall be construed to—
5	"(i) permit an issuer to request (or
6	require) the results of the services referred
7	to in such subparagraph; or
8	"(ii) require that an issuer make pay-
9	ment for services described in such sub-
10	paragraph where the individual involved
11	has refused to provide evidence of the per-
12	formance of such services pursuant to a re-
13	quest by the issuer in accordance with such
14	subparagraph.
15	"(5) Information for payment of other
16	CLAIMS.—With respect to the payment of claims for
17	benefits other than genetic services, an issuer of a
18	medicare supplemental policy may request that an
19	individual provide predictive genetic information so
20	long as such information—
21	"(A) is used solely for the payment of a
22	claim;
23	"(B) is limited to information that is di-
24	rectly related to and necessary for the payment
25	of such claim and the claim would otherwise be

denied but for the predictive genetic information; and

"(C) is used only by an individual (or individuals) within such issuer who needs access to such information for purposes of payment of a claim.

## "(6) Rules of Construction.—

"(A) Collection or disclosure authorization for the collection or disclosure authorization for the collection or disclosure of predictive genetic information.

"(B) DISCLOSURE FOR HEALTH CARE TREATMENT.—Nothing in this section shall be construed to limit or restrict the disclosure of predictive genetic information from a health care provider to another health care provider for the purpose of providing health care treatment to the individual involved.

"(7) VIOLATION OF GENETIC DISCRIMINATION OR GENETIC DISCLOSURE PROVISIONS.—In any action under this subsection against any administrator

of a medicare supplemental policy (including any third party administrator or other person acting for or on behalf of such policy) alleging a violation of 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.

- "(8) CIVIL PENALTY.—The monetary provisions of section 308(b)(2)(C) of Public Law 101–336 (42 U.S.C. 12188(b)) shall apply for purposes of the Secretary enforcing the provisions of this subsection, except that any such relief awarded shall be paid only into the general fund of the Treasury.
- "(9) Special rule in case of genetic information.—This subsection (relating to genetic information or information about a request for, or the receipt of, genetic services by an individual or a family member of such individual) shall not be construed to supersede any provision of State law which establishes, implements, or continues in effect a standard, requirement, or remedy that more completely—
- "(A) protects the confidentiality of genetic
   information (including information about a re-

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1	quest for, or the receipt of, genetic services by
2	an individual or a family member of such indi-
3	vidual) or the privacy of an individual or a fam-
4	ily member of the individual with respect to ge-
5	netic information (including information about
6	a request for, or the receipt of, genetic services
7	by an individual or a family member of such in-
8	dividual) than does this subsection; or
9	"(B) prohibits discrimination on the basis
10	of genetic information than does this sub-
11	section.
12	"(10) Definitions.—In this subsection:
13	"(A) Controlled Group.—The term
14	'controlled group' means any group treated as
15	a single employer under subsection (b), (c),
16	(m), or (o) of section 414 of the Internal Rev-
17	enue Code of 1986.
18	"(B) Family member.—The term 'family
19	member' means with respect to an individual—
20	"(i) the spouse of the individual;
21	"(ii) a dependent child of the indi-
22	vidual, including a child who is born to or
23	placed for adoption with the individual;
24	and

1	"(iii) all other individuals related by
2	blood to the individual or 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.—The term 'genetic
19	test' means the analysis of human DNA, RNA,
20	chromosomes, proteins, and certain metabolites
21	in order to detect genotypes, mutations, or
22	chromosomal changes.
23	"(F) Issuer of a medicare supple-
24	MENTAL POLICY.—The term 'issuer of a medi-
25	care supplemental policy' includes a third-party

1	administrator or other person acting for or on
2	behalf of such issuer.
3	"(G) Predictive Genetic Informa-
4	TION.—
5	"(i) In General.—The term 'pre-
6	dictive genetic information' means—
7	"(I) information about an indi-
8	vidual's genetic tests;
9	"(II) information about genetic
10	tests of family members of the indi-
11	vidual; or
12	"(III) information about the oc-
13	currence of a disease or disorder in
14	family members.
15	"(ii) Limitations.—The term 'pre-
16	dictive genetic information' shall not
17	include—
18	"(I) information about the sex or
19	age of the individual;
20	"(II) information about chemical,
21	blood, or urine analyses of the indi-
22	vidual, unless these analyses are ge-
23	netic tests; or
24	"(III) information about physical
25	exams of the individual, and other in-

- formation relevant to determining the
  current health status of the individual.".
- 4 (2) CONFORMING AMENDMENT.—Section
  5 1882(o) of the Social Security Act (42 U.S.C.
  6 1395ss(o)) is amended by adding at the end the following:
  - "(4) The issuer of the medicare supplemental policy complies with subsection (s)(2)(E) and subsection (v).".
  - (3) Effective date.—The amendments made by this subsection shall apply with respect to an issuer of a medicare supplemental policy for policy years beginning after October 1, 2000.

# (c) Transition Provisions.—

(1) IN GENERAL.—If the Secretary of Health and Human Services identifies a State as requiring a change to its statutes or regulations to conform its regulatory program to the changes made by this section, the State regulatory program shall not be considered to be out of compliance with the requirements of section 1882 of the Social Security Act due solely to failure to make such change until the date specified in paragraph (4).

(2) NAIC STANDARDS.—If, not later than June 30, 2000, the National Association of Insurance Commissioners (in this subsection referred to as the "NAIC") modifies its NAIC Model Regulation relating to section 1882 of the Social Security Act (referred to in such section as the 1991 NAIC Model Regulation, as subsequently modified) to conform to the amendments made by this section, such revised regulation incorporating the modifications shall be considered to be the applicable NAIC model regulation (including the revised NAIC model regulation and the 1991 NAIC Model Regulation) for the purposes of such section.

(3) Secretary standards.—If the NAIC does not make the modifications described in paragraph (2) within the period specified in such paragraph, the Secretary of Health and Human Services shall, not later than October 1, 2000, make the modifications described in such paragraph and such revised regulation incorporating the modifications shall be considered to be the appropriate regulation for the purposes of such section.

# (4) Date specified.—

1	(A) In general.—Subject to subpara-
2	graph (B), the date specified in this paragraph
3	for a State is the earlier of—
4	(i) the date the State changes its stat-
5	utes or regulations to conform its regu-
6	latory program to the changes made by
7	this section, or
8	(ii) October 1, 2000.
9	(B) Additional legislative action re-
10	QUIRED.—In the case of a State which the Sec-
11	retary identifies as—
12	(i) requiring State legislation (other
13	than legislation appropriating funds) to
14	conform its regulatory program to the
15	changes made in this section, but
16	(ii) having a legislature which is not
17	scheduled to meet in 2000 in a legislative
18	session in which such legislation may be
19	considered,
20	the date specified in this paragraph is the first
21	day of the first calendar quarter beginning after
22	the close of the first legislative session of the
23	State legislature that begins on or after July 1,
24	2000. For purposes of the previous sentence, in
25	the case of a State that has a 2-year legislative

1	session, each year of such session shall be
2	deemed to be a separate regular session of the
3	State legislature.
4	TITLE II—PROHIBITION OF EM-
5	PLOYMENT DISCRIMINATION
6	ON THE BASIS OF PRE-
7	DICTIVE GENETIC INFORMA-
8	TION
9	SEC. 201. DEFINITIONS.
10	In this title:
11	(1) Employee; employer; employment
12	AGENCY; LABOR ORGANIZATION; MEMBER.—The
13	terms "employee", "employer", "employment agen-
14	cy", and "labor organization" have the meanings
15	given such terms in section 701 of the Civil Rights
16	Act of 1964 (42 U.S.C. 2000e), except that the
17	terms "employee" and "employer" shall also include
18	the meanings given such terms in section 717 of the
19	Civil Rights Act of 1964 (42 U.S.C. 2000e–16). The
20	terms "employee" and "member" include an appli-
21	cant for employment and an applicant for member-
22	ship in a labor organization, respectively.
23	(2) Family member.—The term "family mem-
24	ber" means with respect to an individual—
25	(A) the spouse of the individual:

- 1 (B) a dependent child of the individual, in-2 cluding a child who is born to or placed for 3 adoption with the individual; and
  - (C) all other individuals related by blood to the individual or the spouse or child described in subparagraph (A) or (B).
  - (3) Genetic monitoring.—The term "genetic monitoring" means the periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of employment due to exposure to toxic substances in the workplace, in order to identify, evaluate, and respond to the effects of or control adverse environmental exposures in the workplace.
  - (4) Genetic services.—The term "genetic services" means health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counseling.
  - (5) GENETIC TEST.—The term "genetic test" means the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order

1	to detect genotypes, mutations, or chromosomal
2	changes.
3	(6) Predictive genetic information.—
4	(A) IN GENERAL.—The term "predictive
5	genetic information" means—
6	(i) information about an individual's
7	genetic tests;
8	(ii) information about genetic tests of
9	family members of the individual; or
10	(iii) information about the occurrence
11	of a disease or disorder in family members.
12	(B) Limitations.—The term "predictive
13	genetic information" shall not include—
14	(i) information about the sex or age of
15	the individual;
16	(ii) information about chemical, blood
17	or urine analyses of the individual, unless
18	these analyses are genetic tests; or
19	(iii) information about physical exams
20	of the individual, and other information
21	relevant to determining the current health
22	status of the individual.
23	SEC. 202. EMPLOYER PRACTICES.
24	(a) In General.—It shall be an unlawful employ-
25	ment practice for an employer—

- (1) to fail or refuse to hire or to discharge any individual, or otherwise to discriminate against any individual with respect to the compensation, terms, conditions, or privileges of employment of the individual, because of predictive genetic information with respect to the individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual;
  - (2) to limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any individual of employment opportunities or otherwise adversely affect the status of the individual as an employee, because of predictive genetic information with respect to the individual, or information about a request for or the receipt of genetic services by such individual or family member of such individual; or
  - (3) to request, require, collect or purchase predictive genetic information with respect to an individual or a family member of the individual except—
  - (A) where used for genetic monitoring of biological effects of toxic substances in the workplace, but only if—

1	(i) the employee has provided prior,
2	knowing, voluntary, and written authoriza-
3	tion;
4	(ii) the employee is informed of indi-
5	vidual monitoring results;
6	(iii) the monitoring conforms to any
7	genetic monitoring regulations that may be
8	promulgated by the Secretary of Labor
9	pursuant to the Occupational Safety and
10	Health Act of 1970 (29 U.S.C. 651 et
11	seq.) or the Federal Mine Safety and
12	Health Act of 1977 (30 U.S.C. 801 et
13	seq.); and
14	(iv) the employer, excluding any li-
15	censed health care professional that is in-
16	volved in the genetic monitoring program,
17	receives the results of the monitoring only
18	in aggregate terms that do not disclose the
19	identity of specific employees; or
20	(B) where genetic services are offered by
21	the employer and the employee provides prior,
22	knowing, voluntary, and written authorization,
23	and only the employee or family member of
24	such employee receives the results of such serv-
25	ices.

- 1 (b) Limitation.—In the case of predictive genetic in-
- 2 formation to which subparagraph (A) or (B) of subsection
- 3 (a)(3) applies, such information may not be used in viola-
- 4 tion of paragraph (1) or (2) of subsection (a).

#### 5 SEC. 203. EMPLOYMENT AGENCY PRACTICES.

- 6 It shall be an unlawful employment practice for an 7 employment agency—
- (1) to fail or refuse to refer for employment, or otherwise to discriminate against, any individual because of predictive genetic information with respect to the individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual);
  - (2) to limit, segregate, or classify individuals or fail or refuse to refer for employment any individual in any way that would deprive or tend to deprive any individual of employment opportunities or would limit the employment opportunities or otherwise adversely affect the status of the individual as an employee, because of predictive genetic information with respect to the individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual);

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- 1 (3) to request, require, collect or purchase pre-2 dictive genetic information with respect to an indi-3 vidual (or information about a request for or the re-4 ceipt of genetic services by such individual or family 5 member of such individual); or
- 6 (4) to cause or attempt to cause an employer to
  7 discriminate against an individual in violation of this
  8 title.

## 9 SEC. 204. LABOR ORGANIZATION PRACTICES.

- 10 It shall be an unlawful employment practice for a 11 labor organization—
  - (1) to exclude or to expel from the membership of the organization, or otherwise to discriminate against, any individual because of predictive genetic information with respect to the individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual);
    - (2) to limit, segregate, or classify the members of the organization, or fail or refuse to refer for employment any individual, in any way that would deprive or tend to deprive any individual of employment opportunities, or would limit the employment opportunities or otherwise adversely affect the status of the individual as an employee, because of pre-

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- dictive genetic information with respect to the individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual);
  - (3) to request, require, collect or purchase predictive genetic information with respect to an individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual); or
- 10 (4) to cause or attempt to cause an employer to 11 discriminate against an individual in violation of this 12 title.

#### 13 SEC. 205. TRAINING PROGRAMS.

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- It shall be an unlawful employment practice for any 15 employer, labor organization, or joint labor-management 16 committee controlling apprenticeship or other training or 17 retraining, including on-the-job training programs—
- (1) to discriminate against any individual because of predictive genetic information with respect
  to the individual (or information about a request for
  or the receipt of genetic services by such individual),
  in admission to, or employment in, any program established to provide apprenticeship or other training
  or retraining;

- 1 (2) to limit, segregate, or classify the members 2 of the organization, or fail or refuse to refer for em-3 ployment any individual, in any way that would deprive or tend to deprive any individual of employ-5 ment opportunities, or would limit the employment 6 opportunities or otherwise adversely affect the status 7 of the individual as an employee, because of pre-8 dictive genetic information with respect to the indi-9 vidual (or information about a request for or receipt 10 of genetic services by such individual or family mem-11 ber of such individual);
  - (3) to request, require, collect or purchase predictive genetic information with respect to an individual (or information about a request for or receipt of genetic services by such individual or family member of such individual); or
- 17 (4) to cause or attempt to cause an employer to 18 discriminate against an individual in violation of this 19 title.

### 20 SEC. 206. MAINTENANCE AND DISCLOSURE OF PREDICTIVE

### 21 GENETIC INFORMATION.

22 (a) Maintenance of Predictive Genetic Infor-23 Mation.—If an employer possesses predictive genetic in-24 formation about an employee (or information about a re-25 quest for or receipt of genetic services by such employee

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- 1 or family member of such employee), such information
- 2 shall be treated or maintained as part of the employee's
- 3 confidential medical records.
- 4 (b) Disclosure of Predictive Genetic Informa-
- 5 TION.—An employer shall not disclose predictive genetic
- 6 information (or information about a request for or receipt
- 7 of genetic services by such employee or family member of
- 8 such employee) except—
- 9 (1) to the employee who is the subject of the in-
- formation at the request of the employee;
- 11 (2) to an occupational or other health re-
- searcher if the research is conducted in compliance
- with the regulations and protections provided for
- under part 46 of title 45, Code of Federal Regula-
- tions;
- 16 (3) under legal compulsion of a Federal court
- order, except that if the court order was secured
- without the knowledge of the individual to whom the
- information refers, the employer shall provide the in-
- dividual with adequate notice to challenge the court
- order unless the court order also imposes confiden-
- 22 tiality requirements; and
- 23 (4) to government officials who are inves-
- tigating compliance with this Act if the information
- is relevant to the investigation.

#### 1 SEC. 207. CIVIL ACTION.

- 2 (a) In General.—One or more employees, members
- 3 of a labor organization, or participants in training pro-
- 4 grams may bring an action in a Federal or State court
- 5 of competent jurisdiction against an employer, employ-
- 6 ment agency, labor organization, or joint labor-manage-
- 7 ment committee or training program who commits a viola-
- 8 tion of this title.
- 9 (b) Enforcement by the Equal Employment
- 10 Opportunity Commission.—
- 11 (1) IN GENERAL.—The powers, remedies, and
- procedures set forth in sections 705, 706, 707, 709,
- 13 710, and 717 of the Civil Rights Act of 1964 (42)
- 14 U.S.C. 2000e-4, 2000e-5, 2000e-6, 2000e-8,
- 15 2000e-9, and 2000e-16) shall be the powers, rem-
- edies, and procedures provided to the Equal Employ-
- 17 ment Opportunity Commission to enforce this title.
- The Commission may promulgate regulations to im-
- 19 plement these powers, remedies, and procedures.
- 20 (2) Exhaustion of Remedies.—Nothing in
- 21 this subsection shall be construed to require that an
- individual exhaust the administrative remedies avail-
- able through the Equal Employment Opportunity
- 24 Commission prior to commencing a civil action
- 25 under this section, except that if an individual files
- a charge of discrimination with the Commission that

1 alleges a violation of this title, the individual shall 2 administrative remedies exhaust the available 3 through the Commission prior to commencing a civil action under this section. 5 (c) Remedy.—A Federal or State court may award any appropriate legal or equitable relief under this section. 6 7 Such relief may include a requirement for the payment 8 of attorney's fees and costs, including the costs of experts. SEC. 208. CONSTRUCTION. 10 Nothing in this title shall be construed to— 11 (1) limit the rights or protections of an indi-12 vidual under the Americans with Disabilities Act of 13 1990 (42 U.S.C. 12101 et seq.), including coverage 14 afforded to individuals under section 102 of such 15 Act; 16 (2) limit the rights or protections of an indi-17 vidual under the Rehabilitation Act of 1973 (29) 18 U.S.C. 701 et seq.); 19 (3) limit the rights or protections of an indi-20 vidual under any other Federal or State statute that 21 provides equal or greater protection to an individual 22 than the rights accorded under this Act; 23 (4) apply to the Armed Forces Repository of 24 Specimen Samples for the Identification of Remains;

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or

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

## 6 SEC. 209. AUTHORIZATION OF APPROPRIATIONS.

- 7 There are authorized to be appropriated such sums
- 8 as may be necessary to carry out this title.
- 9 SEC. 210. EFFECTIVE DATE.
- This title shall become effective on October 1, 2000.

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