

Public Law 110–233
110th Congress

An Act

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

May 21, 2008
[H.R. 493]

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) **SHORT TITLE.**—This Act may be cited as the “Genetic Information Nondiscrimination Act of 2008”.

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

- Sec. 1. Short title; table of contents.
- Sec. 2. Findings.

TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE

- Sec. 101. Amendments to Employee Retirement Income Security Act of 1974.
- Sec. 102. Amendments to the Public Health Service Act.
- Sec. 103. Amendments to the Internal Revenue Code of 1986.
- Sec. 104. Amendments to title XVIII of the Social Security Act relating to medigap.
- Sec. 105. Privacy and confidentiality.
- Sec. 106. Assuring coordination.

TITLE II—PROHIBITING EMPLOYMENT DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION

- Sec. 201. Definitions.
- Sec. 202. Employer practices.
- Sec. 203. Employment agency practices.
- Sec. 204. Labor organization practices.
- Sec. 205. Training programs.
- Sec. 206. Confidentiality of genetic information.
- Sec. 207. Remedies and enforcement.
- Sec. 208. Disparate impact.
- Sec. 209. Construction.
- Sec. 210. Medical information that is not genetic information.
- Sec. 211. Regulations.
- Sec. 212. Authorization of appropriations.
- Sec. 213. Effective date.

TITLE III—MISCELLANEOUS PROVISIONS

- Sec. 301. Severability.
- Sec. 302. Child labor protections.

SEC. 2. FINDINGS.

Congress makes the following findings:

(1) Deciphering the sequence of the human genome and other advances in genetics open major new opportunities for medical progress. New knowledge about the genetic basis of illness will allow for earlier detection of illnesses, often before symptoms have begun. Genetic testing can allow individuals to take steps to reduce the likelihood that they will contract

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42 USC 2000ff
note.

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a particular disorder. New knowledge about genetics may allow for the development of better therapies that are more effective against disease or have fewer side effects than current treatments. These advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment.

(2) The early science of genetics became the basis of State laws that provided for the sterilization of persons having presumed genetic “defects” such as mental retardation, mental disease, epilepsy, blindness, and hearing loss, among other conditions. The first sterilization law was enacted in the State of Indiana in 1907. By 1981, a majority of States adopted sterilization laws to “correct” apparent genetic traits or tendencies. Many of these State laws have since been repealed, and many have been modified to include essential constitutional requirements of due process and equal protection. However, the current explosion in the science of genetics, and the history of sterilization laws by the States based on early genetic science, compels Congressional action in this area.

(3) Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Because some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information. This form of discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. Once again, State legislatures began to enact discriminatory laws in the area, and in the early 1970s began mandating genetic screening of all African Americans for sickle cell anemia, leading to discrimination and unnecessary fear. To alleviate some of this stigma, Congress in 1972 passed the National Sickle Cell Anemia Control Act, which withholds Federal funding from States unless sickle cell testing is voluntary.

(4) Congress has been informed of examples of genetic discrimination in the workplace. These include the use of pre-employment genetic screening at Lawrence Berkeley Laboratory, which led to a court decision in favor of the employees in that case *Norman-Bloodsaw v. Lawrence Berkeley Laboratory* (135 F.3d 1260, 1269 (9th Cir. 1998)). Congress clearly has a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance.

(5) Federal law addressing genetic discrimination in health insurance and employment is incomplete in both the scope and depth of its protections. Moreover, while many States have enacted some type of genetic non-discrimination law, these laws vary widely with respect to their approach, application, and level of protection. Congress has collected substantial evidence that the American public and the medical community find the existing patchwork of State and Federal laws to be confusing and inadequate to protect them from discrimination. Therefore Federal legislation establishing a national and uniform basic standard is necessary to fully protect the public from discrimination and allay their concerns about the potential

for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.

TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE

SEC. 101. AMENDMENTS TO EMPLOYEE RETIREMENT INCOME SECURITY ACT OF 1974.

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

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

(2) by adding at the end the following:

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

“(A) **IN GENERAL.**—For purposes of this section, a group health plan, and a health insurance issuer offering group health insurance coverage in connection with a group health plan, may not adjust premium or contribution amounts for the group covered under such plan on the basis of genetic information.

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

(b) **LIMITATIONS ON GENETIC TESTING; PROHIBITION ON COLLECTION OF GENETIC INFORMATION; APPLICATION TO ALL PLANS.**—Section 702 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1182) is amended by adding at the end the following:

“(c) **GENETIC TESTING.**—

“(1) **LIMITATION ON REQUESTING OR REQUIRING GENETIC TESTING.**—A group health plan, and 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.**—Paragraph (1) shall not be construed to limit the authority of a health care professional who is providing health care services to an individual to request that such individual undergo a genetic test.

“(3) **RULE OF CONSTRUCTION REGARDING PAYMENT.**—

“(A) **IN GENERAL.**—Nothing in paragraph (1) shall be construed to preclude a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, from obtaining and using the results of a genetic test in making a determination regarding payment (as such term is defined for the purposes of applying the regulations promulgated by the

Secretary of Health and Human Services under part C of title XI of the Social Security Act and section 264 of the Health Insurance Portability and Accountability Act of 1996, as may be revised from time to time) consistent with subsection (a).

“(B) LIMITATION.—For purposes of subparagraph (A), a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, may request only the minimum amount of information necessary to accomplish the intended purpose.

“(4) RESEARCH EXCEPTION.—Notwithstanding paragraph (1), a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, may request, but not require, that a participant or beneficiary undergo a genetic test if each of the following conditions is met:

“(A) The request is made, in writing, pursuant to research that complies with part 46 of title 45, Code of Federal Regulations, or equivalent Federal regulations, and any applicable State or local law or regulations for the protection of human subjects in research.

“(B) The plan or issuer clearly indicates to each participant or beneficiary, or in the case of a minor child, to the legal guardian of such beneficiary, to whom the request is made that—

“(i) compliance with the request is voluntary; and

“(ii) non-compliance will have no effect on enrollment status or premium or contribution amounts.

“(C) No genetic information collected or acquired under this paragraph shall be used for underwriting purposes.

“(D) The plan or issuer notifies the Secretary in writing that the plan or issuer is conducting activities pursuant to the exception provided for under this paragraph, including a description of the activities conducted.

“(E) The plan or issuer complies with such other conditions as the Secretary may by regulation require for activities conducted under this paragraph.

“(d) PROHIBITION ON COLLECTION OF GENETIC INFORMATION.—

“(1) IN GENERAL.—A group health plan, and a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request, require, or purchase genetic information for underwriting purposes (as defined in section 733).

“(2) PROHIBITION ON COLLECTION OF GENETIC INFORMATION PRIOR TO ENROLLMENT.—A group health plan, and a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request, require, or purchase genetic information with respect to any individual prior to such individual’s enrollment under the plan or coverage in connection with such enrollment.

“(3) INCIDENTAL COLLECTION.—If a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, obtains genetic information incidental to the requesting, requiring, or purchasing of other information concerning any individual, such request, requirement, or purchase shall not be considered a violation

Notification.

of paragraph (2) if such request, requirement, or purchase is not in violation of paragraph (1).

“(e) APPLICATION TO ALL PLANS.—The provisions of subsections (a)(1)(F), (b)(3), (c), and (d), and subsection (b)(1) and section 701 with respect to genetic information, shall apply to group health plans and health insurance issuers without regard to section 732(a).”

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

“(f) GENETIC INFORMATION OF A FETUS OR EMBRYO.—Any reference in this part to genetic information concerning an individual or family member of an individual shall—

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

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

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

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

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

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

“(6) GENETIC INFORMATION.—

“(A) IN GENERAL.—The term ‘genetic information’ means, with respect to any individual, information about—

“(i) such individual’s genetic tests,

“(ii) the genetic tests of family members of such individual, and

“(iii) the manifestation of a disease or disorder in family members of such individual.

“(B) INCLUSION OF GENETIC SERVICES AND PARTICIPATION IN GENETIC RESEARCH.—Such term includes, with respect to any individual, any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual.

“(C) EXCLUSIONS.—The term ‘genetic information’ shall not include information about the sex or age of any individual.

“(7) GENETIC TEST.—

“(A) IN GENERAL.—The term ‘genetic test’ means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

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

“(i) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or

“(ii) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.

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

“(A) a genetic test;

“(B) genetic counseling (including obtaining, interpreting, or assessing genetic information); or

“(C) genetic education.

“(9) UNDERWRITING PURPOSES.—The term ‘underwriting purposes’ means, with respect to any group health plan, or health insurance coverage offered in connection with a group health plan—

“(A) rules for, or determination of, eligibility (including enrollment and continued eligibility) for benefits under the plan or coverage;

“(B) the computation of premium or contribution amounts under the plan or coverage;

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

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

(e) ERISA ENFORCEMENT.—Section 502 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1132) is amended—

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

(2) in subsection (b)(3), by striking “The Secretary” and inserting “Except as provided in subsections (c)(9) and (a)(6) (with respect to collecting civil penalties under subsection (c)(9)), the Secretary”; and

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

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

“(A) GENERAL RULE.—The Secretary may impose a penalty against any plan sponsor of a group health plan, or any health insurance issuer offering health insurance coverage in connection with the plan, for any failure by such sponsor or issuer to meet the requirements of subsection (a)(1)(F), (b)(3), (c), or (d) of section 702 or section 701 or 702(b)(1) with respect to genetic information, in connection with the plan.

“(B) AMOUNT.—

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

“(ii) NONCOMPLIANCE PERIOD.—For purposes of this paragraph, the term ‘noncompliance period’ means, with respect to any failure, the period—

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

“(II) ending on the date the failure is corrected.

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

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

“(I) which are not corrected before the date on which the plan receives a notice from the Secretary of such violation; and

“(II) which occurred or continued during the period involved;

the amount of penalty imposed by subparagraph (A) by reason of such failures with respect to such participant or beneficiary shall not be less than \$2,500.

“(ii) HIGHER MINIMUM PENALTY WHERE VIOLATIONS ARE MORE THAN DE MINIMIS.—To the extent violations for which any person is liable under this paragraph for any year are more than de minimis, clause (i) shall be applied by substituting ‘\$15,000’ for ‘\$2,500’ with respect to such person.

“(D) LIMITATIONS.—

“(i) PENALTY NOT TO APPLY WHERE FAILURE NOT DISCOVERED EXERCISING REASONABLE DILIGENCE.—No penalty shall be imposed by subparagraph (A) on any failure during any period for which it is established to the satisfaction of the Secretary that the person otherwise liable for such penalty did not know, and exercising reasonable diligence would not have known, that such failure existed.

“(ii) PENALTY NOT TO APPLY TO FAILURES CORRECTED WITHIN CERTAIN PERIODS.—No penalty shall be imposed by subparagraph (A) on any failure if—

“(I) such failure was due to reasonable cause and not to willful neglect; and

“(II) such failure is corrected during the 30-day period beginning on the first date the person otherwise liable for such penalty knew, or exercising reasonable diligence would have known, that such failure existed.

“(iii) OVERALL LIMITATION FOR UNINTENTIONAL FAILURES.—In the case of failures which are due to reasonable cause and not to willful neglect, the penalty imposed by subparagraph (A) for failures shall not exceed the amount equal to the lesser of—

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

“(II) \$500,000.

“(E) WAIVER BY SECRETARY.—In the case of a failure which is due to reasonable cause and not to willful neglect, the Secretary may waive part or all of the penalty imposed by subparagraph (A) to the extent that the payment of such penalty would be excessive relative to the failure involved.

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

29 USC 1132
note.

(f) REGULATIONS AND EFFECTIVE DATE.—

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

Applicability.

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

SEC. 102. AMENDMENTS TO THE PUBLIC HEALTH SERVICE ACT.

(a) AMENDMENTS RELATING TO THE GROUP MARKET.—

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

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

(B) by adding at the end the following:

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

“(A) IN GENERAL.—For purposes of this section, a group health plan, and health insurance issuer offering group health insurance coverage in connection with a group health plan, may not adjust premium or contribution amounts for the group covered under such plan on the basis of genetic information.

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

(2) LIMITATIONS ON GENETIC TESTING; PROHIBITION ON COLLECTION OF GENETIC INFORMATION; APPLICATION TO ALL PLANS.—Section 2702 of the Public Health Service Act (42 U.S.C. 300gg-1) is amended by adding at the end the following:

“(c) GENETIC TESTING.—

“(1) LIMITATION ON REQUESTING OR REQUIRING GENETIC TESTING.—A group health plan, and 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.—Paragraph (1) shall not be construed to limit the authority of a health care professional who is providing health care services to an individual to request that such individual undergo a genetic test.

“(3) RULE OF CONSTRUCTION REGARDING PAYMENT.—

“(A) IN GENERAL.—Nothing in paragraph (1) shall be construed to preclude a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, from obtaining and using the results of a genetic test in making a determination regarding payment (as such term is defined for the purposes of applying the regulations promulgated by the Secretary under part C of title XI of the Social Security Act and section 264 of the Health Insurance Portability and Accountability Act of 1996, as may be revised from time to time) consistent with subsection (a).

“(B) LIMITATION.—For purposes of subparagraph (A), a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, may request only the minimum amount of information necessary to accomplish the intended purpose.

“(4) RESEARCH EXCEPTION.—Notwithstanding paragraph (1), a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, may request, but not require, that a participant or beneficiary undergo a genetic test if each of the following conditions is met:

“(A) The request is made pursuant to research that complies with part 46 of title 45, Code of Federal Regulations, or equivalent Federal regulations, and any applicable State or local law or regulations for the protection of human subjects in research.

“(B) The plan or issuer clearly indicates to each participant or beneficiary, or in the case of a minor child, to the legal guardian of such beneficiary, to whom the request is made that—

“(i) compliance with the request is voluntary; and

“(ii) non-compliance will have no effect on enrollment status or premium or contribution amounts.

“(C) No genetic information collected or acquired under this paragraph shall be used for underwriting purposes.

“(D) The plan or issuer notifies the Secretary in writing that the plan or issuer is conducting activities pursuant to the exception provided for under this paragraph, including a description of the activities conducted.

“(E) The plan or issuer complies with such other conditions as the Secretary may by regulation require for activities conducted under this paragraph.

“(d) PROHIBITION ON COLLECTION OF GENETIC INFORMATION.—

“(1) IN GENERAL.—A group health plan, and a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request, require, or purchase genetic information for underwriting purposes (as defined in section 2791).

“(2) PROHIBITION ON COLLECTION OF GENETIC INFORMATION PRIOR TO ENROLLMENT.—A group health plan, and a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request, require, or purchase genetic information with respect to any individual prior to such individual’s enrollment under the plan or coverage in connection with such enrollment.

Notification.

“(3) INCIDENTAL COLLECTION.—If a group health plan, or a health insurance issuer offering health insurance coverage in connection with a group health plan, obtains genetic information incidental to the requesting, requiring, or purchasing of other information concerning any individual, such request, requirement, or purchase shall not be considered a violation of paragraph (2) if such request, requirement, or purchase is not in violation of paragraph (1).

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

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

“(f) GENETIC INFORMATION OF A FETUS OR EMBRYO.—Any reference in this part to genetic information concerning an individual or family member of an individual shall—

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

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

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

“(15) FAMILY MEMBER.—The term ‘family member’ means, with respect to any individual—

“(A) a dependent (as such term is used for purposes of section 2701(f)(2)) of such individual; and

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

“(16) GENETIC INFORMATION.—

“(A) IN GENERAL.—The term ‘genetic information’ means, with respect to any individual, information about—

“(i) such individual’s genetic tests,

“(ii) the genetic tests of family members of such individual, and

“(iii) the manifestation of a disease or disorder in family members of such individual.

“(B) INCLUSION OF GENETIC SERVICES AND PARTICIPATION IN GENETIC RESEARCH.—Such term includes, with respect to any individual, any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual.

“(C) EXCLUSIONS.—The term ‘genetic information’ shall not include information about the sex or age of any individual.

“(17) GENETIC TEST.—

“(A) IN GENERAL.—The term ‘genetic test’ means an analysis of human DNA, RNA, chromosomes, proteins, or

metabolites, that detects genotypes, mutations, or chromosomal changes.

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

“(i) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes; or

“(ii) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.

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

“(A) a genetic test;

“(B) genetic counseling (including obtaining, interpreting, or assessing genetic information); or

“(C) genetic education.

“(19) UNDERWRITING PURPOSES.—The term ‘underwriting purposes’ means, with respect to any group health plan, or health insurance coverage offered in connection with a group health plan—

“(A) rules for, or determination of, eligibility (including enrollment and continued eligibility) for benefits under the plan or coverage;

“(B) the computation of premium or contribution amounts under the plan or coverage;

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

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

(5) REMEDIES AND ENFORCEMENT.—Section 2722(b) of the Public Health Service Act (42 U.S.C. 300gg-22(b)) is amended by adding at the end the following:

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

“(A) GENERAL RULE.—In the cases described in paragraph (1), notwithstanding the provisions of paragraph (2)(C), the succeeding subparagraphs of this paragraph shall apply with respect to an action under this subsection by the Secretary with respect to any failure of a health insurance issuer in connection with a group health plan, to meet the requirements of subsection (a)(1)(F), (b)(3), (c), or (d) of section 2702 or section 2701 or 2702(b)(1) with respect to genetic information in connection with the plan.

“(B) AMOUNT.—

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

Penalties.

“(ii) NONCOMPLIANCE PERIOD.—For purposes of this paragraph, the term ‘noncompliance period’ means, with respect to any failure, the period—

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

“(II) ending on the date the failure is corrected.

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

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

“(I) which are not corrected before the date on which the plan receives a notice from the Secretary of such violation; and

“(II) which occurred or continued during the period involved;

the amount of penalty imposed by subparagraph (A) by reason of such failures with respect to such individual shall not be less than \$2,500.

“(ii) HIGHER MINIMUM PENALTY WHERE VIOLATIONS ARE MORE THAN DE MINIMIS.—To the extent violations for which any person is liable under this paragraph for any year are more than de minimis, clause (i) shall be applied by substituting ‘\$15,000’ for ‘\$2,500’ with respect to such person.

“(D) LIMITATIONS.—

“(i) PENALTY NOT TO APPLY WHERE FAILURE NOT DISCOVERED EXERCISING REASONABLE DILIGENCE.—No penalty shall be imposed by subparagraph (A) on any failure during any period for which it is established to the satisfaction of the Secretary that the person otherwise liable for such penalty did not know, and exercising reasonable diligence would not have known, that such failure existed.

“(ii) PENALTY NOT TO APPLY TO FAILURES CORRECTED WITHIN CERTAIN PERIODS.—No penalty shall be imposed by subparagraph (A) on any failure if—

“(I) such failure was due to reasonable cause and not to willful neglect; and

“(II) such failure is corrected during the 30-day period beginning on the first date the person otherwise liable for such penalty knew, or exercising reasonable diligence would have known, that such failure existed.

“(iii) OVERALL LIMITATION FOR UNINTENTIONAL FAILURES.—In the case of failures which are due to reasonable cause and not to willful neglect, the penalty imposed by subparagraph (A) for failures shall not exceed the amount equal to the lesser of—

“(I) 10 percent of the aggregate amount paid or incurred by the employer (or predecessor employer) during the preceding taxable year for group health plans; or

“(II) \$500,000.

“(E) WAIVER BY SECRETARY.—In the case of a failure which is due to reasonable cause and not to willful neglect, the Secretary may waive part or all of the penalty imposed by subparagraph (A) to the extent that the payment of such penalty would be excessive relative to the failure involved.”

(b) AMENDMENT RELATING TO THE INDIVIDUAL MARKET.—

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

- (A) by redesignating such subpart as subpart 2; and
- (B) by adding at the end the following:

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

42 USC
300gg-53.

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

“(1) IN GENERAL.—A health insurance issuer offering health insurance coverage in the individual market may not establish rules for the eligibility (including continued eligibility) of any individual to enroll in individual health insurance coverage based on genetic information.

“(2) RULE OF CONSTRUCTION.—Nothing in paragraph (1) or in paragraphs (1) and (2) of subsection (e) shall be construed to preclude a health insurance issuer from establishing rules for eligibility for an individual to enroll in individual health insurance coverage based on the manifestation of a disease or disorder in that individual, or in a family member of such individual where such family member is covered under the policy that covers such individual.

“(b) PROHIBITION ON GENETIC INFORMATION IN SETTING PREMIUM RATES.—

“(1) IN GENERAL.—A health insurance issuer offering health insurance coverage in the individual market shall not adjust premium or contribution amounts for an individual on the basis of genetic information concerning the individual or a family member of the individual.

“(2) RULE OF CONSTRUCTION.—Nothing in paragraph (1) or in paragraphs (1) and (2) of subsection (e) shall be construed to preclude a health insurance issuer from adjusting premium or contribution amounts for an individual on the basis of a manifestation of a disease or disorder in that individual, or in a family member of such individual where such family member is covered under the policy that covers such individual. In such case, the manifestation of a disease or disorder in one individual cannot also be used as genetic information about other individuals covered under the policy issued to such individual and to further increase premiums or contribution amounts.

“(c) PROHIBITION ON GENETIC INFORMATION AS PREEXISTING CONDITION.—

“(1) IN GENERAL.—A health insurance issuer offering health insurance coverage in the individual market may not, on the basis of genetic information, impose any preexisting condition exclusion (as defined in section 2701(b)(1)(A)) with respect to such coverage.

“(2) RULE OF CONSTRUCTION.—Nothing in paragraph (1) or in paragraphs (1) and (2) of subsection (e) shall be construed to preclude a health insurance issuer from imposing any preexisting condition exclusion for an individual with respect to health insurance coverage on the basis of a manifestation of a disease or disorder in that individual.

“(d) GENETIC TESTING.—

“(1) LIMITATION ON REQUESTING OR REQUIRING 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 genetic test.

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

“(3) RULE OF CONSTRUCTION REGARDING PAYMENT.—

“(A) IN GENERAL.—Nothing in paragraph (1) shall be construed to preclude a health insurance issuer offering health insurance coverage in the individual market from obtaining and using the results of a genetic test in making a determination regarding payment (as such term is defined for the purposes of applying the regulations promulgated by the Secretary under part C of title XI of the Social Security Act and section 264 of the Health Insurance Portability and Accountability Act of 1996, as may be revised from time to time) consistent with subsection (a) and (c).

“(B) LIMITATION.—For purposes of subparagraph (A), a health insurance issuer offering health insurance coverage in the individual market may request only the minimum amount of information necessary to accomplish the intended purpose.

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

“(A) The request is made pursuant to research that complies with part 46 of title 45, Code of Federal Regulations, or equivalent Federal regulations, and any applicable State or local law or regulations for the protection of human subjects in research.

“(B) The issuer clearly indicates to each individual, or in the case of a minor child, to the legal guardian of such child, to whom the request is made that—

“(i) compliance with the request is voluntary; and

“(ii) non-compliance will have no effect on enrollment status or premium or contribution amounts.

“(C) No genetic information collected or acquired under this paragraph shall be used for underwriting purposes.

“(D) The issuer notifies the Secretary in writing that the issuer is conducting activities pursuant to the exception provided for under this paragraph, including a description of the activities conducted.

“(E) The issuer complies with such other conditions as the Secretary may by regulation require for activities conducted under this paragraph.

“(e) PROHIBITION ON COLLECTION OF GENETIC INFORMATION.—

“(1) IN GENERAL.—A health insurance issuer offering health insurance coverage in the individual market shall not request, require, or purchase genetic information for underwriting purposes (as defined in section 2791).

“(2) PROHIBITION ON COLLECTION OF GENETIC INFORMATION PRIOR TO ENROLLMENT.—A health insurance issuer offering

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health insurance coverage in the individual market shall not request, require, or purchase genetic information with respect to any individual prior to such individual's enrollment under the plan in connection with such enrollment.

“(3) INCIDENTAL COLLECTION.—If a health insurance issuer offering health insurance coverage in the individual market obtains genetic information incidental to the requesting, requiring, or purchasing of other information concerning any individual, such request, requirement, or purchase shall not be considered a violation of paragraph (2) if such request, requirement, or purchase is not in violation of paragraph (1).

“(f) GENETIC INFORMATION OF A FETUS OR EMBRYO.—Any reference in this part to genetic information concerning an individual or family member of an individual shall—

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

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

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

“(b) SECRETARIAL ENFORCEMENT AUTHORITY.—The Secretary shall have the same authority in relation to enforcement of the provisions of this part with respect to issuers of health insurance coverage in the individual market in a State as the Secretary has under section 2722(b)(2), and section 2722(b)(3) with respect to violations of genetic nondiscrimination provisions, in relation to the enforcement of the provisions of part A with respect to issuers of health insurance coverage in the small group market in the State.”.

(c) ELIMINATION OF OPTION OF NON-FEDERAL GOVERNMENTAL PLANS TO BE EXCEPTED FROM REQUIREMENTS CONCERNING GENETIC INFORMATION.—Section 2721(b)(2) of the Public Health Service Act (42 U.S.C. 300gg-21(b)(2)) is amended—

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

(2) by adding at the end the following:

“(D) ELECTION NOT APPLICABLE TO REQUIREMENTS CONCERNING GENETIC INFORMATION.—The election described in subparagraph (A) shall not be available with respect to the provisions of subsections (a)(1)(F), (b)(3), (c), and (d) of section 2702 and the provisions of sections 2701 and 2702(b) to the extent that such provisions apply to genetic information.”.

(d) REGULATIONS AND EFFECTIVE DATE.—

(1) REGULATIONS.—Not later than 12 months after the date of enactment of this Act, the Secretary of Health and Human Services shall issue final regulations to carry out the amendments made by this section.

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

42 USC
300gg-1 note.

Applicability.

(A) with respect to group health plans, and health insurance coverage offered in connection with group health plans, for plan years beginning after the date that is 1 year after the date of enactment of this Act; and

(B) with respect to health insurance coverage offered, sold, issued, renewed, in effect, or operated in the individual market after the date that is 1 year after the date of enactment of this Act.

SEC. 103. AMENDMENTS TO THE INTERNAL REVENUE CODE OF 1986.

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

26 USC 9802.

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

(2) by adding at the end the following:

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

“(A) **IN GENERAL.**—For purposes of this section, a group health plan may not adjust premium or contribution amounts for the group covered under such plan on the basis of genetic information.

“(B) **RULE OF CONSTRUCTION.**—Nothing in subparagraph (A) or in paragraphs (1) and (2) of subsection (d) shall be construed to limit the ability of a group health plan to increase the premium for an employer based on the manifestation of a disease or disorder of an individual who is enrolled in the plan. In such case, the manifestation of a disease or disorder in one individual cannot also be used as genetic information about other group members and to further increase the premium for the employer.”.

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

“(c) **GENETIC TESTING.**—

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

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

“(3) **RULE OF CONSTRUCTION REGARDING PAYMENT.**—

“(A) **IN GENERAL.**—Nothing in paragraph (1) shall be construed to preclude a group health plan from obtaining and using the results of a genetic test in making a determination regarding payment (as such term is defined for the purposes of applying the regulations promulgated by the Secretary of Health and Human Services under part C of title XI of the Social Security Act and section 264 of the Health Insurance Portability and Accountability Act of 1996, as may be revised from time to time) consistent with subsection (a).

“(B) LIMITATION.—For purposes of subparagraph (A), a group health plan may request only the minimum amount of information necessary to accomplish the intended purpose.

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

“(A) The request is made pursuant to research that complies with part 46 of title 45, Code of Federal Regulations, or equivalent Federal regulations, and any applicable State or local law or regulations for the protection of human subjects in research.

“(B) The plan clearly indicates to each participant or beneficiary, or in the case of a minor child, to the legal guardian of such beneficiary, to whom the request is made that—

“(i) compliance with the request is voluntary; and

“(ii) non-compliance will have no effect on enrollment status or premium or contribution amounts.

“(C) No genetic information collected or acquired under this paragraph shall be used for underwriting purposes.

“(D) The plan notifies the Secretary in writing that the plan is conducting activities pursuant to the exception provided for under this paragraph, including a description of the activities conducted.

Notification.

“(E) The plan complies with such other conditions as the Secretary may by regulation require for activities conducted under this paragraph.

“(d) PROHIBITION ON COLLECTION OF GENETIC INFORMATION.—

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

“(2) PROHIBITION ON COLLECTION OF GENETIC INFORMATION PRIOR TO ENROLLMENT.—A group health plan shall not request, require, or purchase genetic information with respect to any individual prior to such individual’s enrollment under the plan or in connection with such enrollment.

“(3) INCIDENTAL COLLECTION.—If a group health plan obtains genetic information incidental to the requesting, requiring, or purchasing of other information concerning any individual, such request, requirement, or purchase shall not be considered a violation of paragraph (2) if such request, requirement, or purchase is not in violation of paragraph (1).

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

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

“(f) GENETIC INFORMATION OF A FETUS OR EMBRYO.—Any reference in this chapter to genetic information concerning an individual or family member of an individual shall—

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

information of any fetus carried by such pregnant woman; and

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

26 USC 9832.

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

“(6) FAMILY MEMBER.—The term ‘family member’ means, with respect to any individual—

“(A) a dependent (as such term is used for purposes of section 9801(f)(2)) of such individual, and

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

“(7) GENETIC INFORMATION.—

“(A) IN GENERAL.—The term ‘genetic information’ means, with respect to any individual, information about—

“(i) such individual’s genetic tests,

“(ii) the genetic tests of family members of such individual, and

“(iii) the manifestation of a disease or disorder in family members of such individual.

“(B) INCLUSION OF GENETIC SERVICES AND PARTICIPATION IN GENETIC RESEARCH.—Such term includes, with respect to any individual, any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual.

“(C) EXCLUSIONS.—The term ‘genetic information’ shall not include information about the sex or age of any individual.

“(8) GENETIC TEST.—

“(A) IN GENERAL.—The term ‘genetic test’ means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

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

“(i) an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes, or

“(ii) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.

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

“(A) a genetic test;

“(B) genetic counseling (including obtaining, interpreting, or assessing genetic information); or

“(C) genetic education.

“(10) UNDERWRITING PURPOSES.—The term ‘underwriting purposes’ means, with respect to any group health plan, or health insurance coverage offered in connection with a group health plan—

“(A) rules for, or determination of, eligibility (including enrollment and continued eligibility) for benefits under the plan or coverage;

“(B) the computation of premium or contribution amounts under the plan or coverage;

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

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

(e) ENFORCEMENT.—

(1) IN GENERAL.—Subchapter C of chapter 100 of the Internal Revenue Code of 1986 (relating to general provisions) is amended by adding at the end the following new section:

“SEC. 9834. ENFORCEMENT.

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

(2) CONFORMING AMENDMENT.—The table of sections for subchapter C of chapter 100 of such Code is amended by adding at the end the following new item:

“Sec. 9834. Enforcement.”.

(f) REGULATIONS AND EFFECTIVE DATE.—

(1) REGULATIONS.—The Secretary of the Treasury shall issue final regulations or other guidance not later than 12 months after the date of the enactment of this Act to carry out the amendments made by this section.

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

26 USC 9802
note.

Applicability.

SEC. 104. AMENDMENTS TO TITLE XVIII OF THE SOCIAL SECURITY ACT RELATING TO MEDIGAP.

(a) NONDISCRIMINATION.—Section 1882(s)(2) of the Social Security Act (42 U.S.C. 1395ss(s)(2)) is amended by adding at the end the following:

“(E) An issuer of a medicare supplemental policy shall not deny or condition the issuance or effectiveness of the policy (including the imposition of any exclusion of benefits under the policy based on a pre-existing condition) and shall not discriminate in the pricing of the policy (including the adjustment of premium rates) of an individual on the basis of the genetic information with respect to such individual.

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

“(i) denying or conditioning the issuance or effectiveness of the policy or increasing the premium for an employer based on the manifestation of a disease or disorder of an individual who is covered under the policy; or

“(ii) increasing the premium for any policy issued to an individual based on the manifestation of a disease

or disorder of an individual who is covered under the policy (in such case, the manifestation of a disease or disorder in one individual cannot also be used as genetic information about other group members and to further increase the premium for the employer).”.

(b) LIMITATIONS ON GENETIC TESTING AND GENETIC INFORMATION.—

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

“(x) LIMITATIONS ON GENETIC TESTING AND INFORMATION.—

“(1) GENETIC TESTING.—

“(A) LIMITATION ON REQUESTING OR REQUIRING GENETIC TESTING.—An issuer of a medicare supplemental policy shall not request or require an individual or a family member of such individual to undergo a genetic test.

“(B) RULE OF CONSTRUCTION.—Subparagraph (A) shall not be construed to limit the authority of a health care professional who is providing health care services to an individual to request that such individual undergo a genetic test.

“(C) RULE OF CONSTRUCTION REGARDING PAYMENT.—

“(i) IN GENERAL.—Nothing in subparagraph (A) shall be construed to preclude an issuer of a medicare supplemental policy from obtaining and using the results of a genetic test in making a determination regarding payment (as such term is defined for the purposes of applying the regulations promulgated by the Secretary under part C of title XI and section 264 of the Health Insurance Portability and Accountability Act of 1996, as may be revised from time to time) consistent with subsection (s)(2)(E).

“(ii) LIMITATION.—For purposes of clause (i), an issuer of a medicare supplemental policy may request only the minimum amount of information necessary to accomplish the intended purpose.

“(D) RESEARCH EXCEPTION.—Notwithstanding subparagraph (A), an issuer of a medicare supplemental policy may request, but not require, that an individual or a family member of such individual undergo a genetic test if each of the following conditions is met:

“(i) The request is made pursuant to research that complies with part 46 of title 45, Code of Federal Regulations, or equivalent Federal regulations, and any applicable State or local law or regulations for the protection of human subjects in research.

“(ii) The issuer clearly indicates to each individual, or in the case of a minor child, to the legal guardian of such child, to whom the request is made that—

“(I) compliance with the request is voluntary;

and

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

“(iii) No genetic information collected or acquired under this subparagraph shall be used for underwriting, determination of eligibility to enroll or maintain enrollment status, premium rating, or the creation, renewal, or replacement of a plan, contract, or coverage for health insurance or health benefits.

“(iv) The issuer notifies the Secretary in writing that the issuer is conducting activities pursuant to the exception provided for under this subparagraph, including a description of the activities conducted.

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

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

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

“(B) PROHIBITION ON COLLECTION OF GENETIC INFORMATION PRIOR TO ENROLLMENT.—An issuer of a medicare supplemental policy shall not request, require, or purchase genetic information with respect to any individual prior to such individual’s enrollment under the policy in connection with such enrollment.

“(C) INCIDENTAL COLLECTION.—If an issuer of a medicare supplemental policy obtains genetic information incidental to the requesting, requiring, or purchasing of other information concerning any individual, such request, requirement, or purchase shall not be considered a violation of subparagraph (B) if such request, requirement, or purchase is not in violation of subparagraph (A).

“(3) DEFINITIONS.—In this subsection:

“(A) FAMILY MEMBER.—The term ‘family member’ means with respect to an individual, any other individual who is a first-degree, second-degree, third-degree, or fourth-degree relative of such individual.

“(B) GENETIC INFORMATION.—

“(i) IN GENERAL.—The term ‘genetic information’ means, with respect to any individual, information about—

“(I) such individual’s genetic tests,

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

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

“(ii) INCLUSION OF GENETIC SERVICES AND PARTICIPATION IN GENETIC RESEARCH.—Such term includes, with respect to any individual, any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual.

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

“(C) GENETIC TEST.—

“(i) IN GENERAL.—The term ‘genetic test’ means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

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

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

“(II) an analysis of proteins or metabolites that is directly related to a manifested disease, disorder, or pathological condition that could reasonably be detected by a health care professional with appropriate training and expertise in the field of medicine involved.

“(D) GENETIC SERVICES.—The term ‘genetic services’ means—

“(i) a genetic test;

“(ii) genetic counseling (including obtaining, interpreting, or assessing genetic information); or

“(iii) genetic education.

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

“(i) rules for, or determination of, eligibility (including enrollment and continued eligibility) for benefits under the policy;

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

“(iii) the application of any pre-existing condition exclusion under the policy; and

“(iv) other activities related to the creation, renewal, or replacement of a contract of health insurance or health benefits.

“(F) ISSUER OF A MEDICARE SUPPLEMENTAL POLICY.—

The term ‘issuer of a medicare supplemental policy’ includes a third-party administrator or other person acting for or on behalf of such issuer.”.

(2) APPLICATION TO GENETIC INFORMATION OF A FETUS OR EMBRYO.—Section 1882(x) of such Act, as added by paragraph (1), is further amended by adding at the end the following:

“(4) GENETIC INFORMATION OF A FETUS OR EMBRYO.—Any reference in this section to genetic information concerning an individual or family member of an individual shall—

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

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

(3) CONFORMING AMENDMENT.—Section 1882(o) of the Social Security Act (42 U.S.C. 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 (x).”.

(c) **EFFECTIVE DATE.**—The amendments made by this section shall apply with respect to an issuer of a medicare supplemental policy for policy years beginning on or after the date that is 1 year after the date of enactment of this Act. Applicability.
42 USC
1395ss note.

(d) **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). 42 USC
1395ss note.

(2) **NAIC STANDARDS.**—If, not later than October 31, 2008, 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. Deadline.

(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 July 1, 2009, 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. Deadline.

(4) **DATE SPECIFIED.**—

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

- (i) the date the State changes its statutes or regulations to conform its regulatory program to the changes made by this section, or
- (ii) July 1, 2009.

(B) **ADDITIONAL LEGISLATIVE ACTION REQUIRED.**—In the case of a State which the Secretary identifies as—

- (i) requiring State legislation (other than legislation appropriating funds) to conform its regulatory program to the changes made in this section, but
- (ii) having a legislature which is not scheduled to meet in 2009 in a legislative session in which such legislation may be considered, the date specified in this paragraph is the first day of the first calendar quarter beginning after the close of the first legislative session of the State legislature that begins on or after July 1, 2009. For purposes of the previous sentence, in the case of a State that has a 2-year legislative session, each year of such session shall be deemed to be a separate regular session of the State legislature.

SEC. 105. PRIVACY AND CONFIDENTIALITY.

(a) **IN GENERAL.**—Part C of title XI of the Social Security Act is amended by adding at the end the following new section:

“APPLICATION OF HIPAA REGULATIONS TO GENETIC INFORMATION

42 USC 1320d-9.

“SEC. 1180. (a) IN GENERAL.—The Secretary shall revise the HIPAA privacy regulation (as defined in subsection (b)) so it is consistent with the following:

“(1) Genetic information shall be treated as health information described in section 1171(4)(B).

“(2) The use or disclosure by a covered entity that is a group health plan, health insurance issuer that issues health insurance coverage, or issuer of a medicare supplemental policy of protected health information that is genetic information about an individual for underwriting purposes under the group health plan, health insurance coverage, or medicare supplemental policy shall not be a permitted use or disclosure.

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

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

“(2) GROUP HEALTH PLAN; HEALTH INSURANCE COVERAGE; MEDICARE SUPPLEMENTAL POLICY.—The terms ‘group health plan’ and ‘health insurance coverage’ have the meanings given such terms under section 2791 of the Public Health Service Act (42 U.S.C. 300gg-91), and the term ‘medicare supplemental policy’ has the meaning given such term in section 1882(g).

“(3) HIPAA PRIVACY REGULATION.—The term ‘HIPAA privacy regulation’ means the regulations promulgated by the Secretary under this part and section 264 of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d-2 note).

“(4) UNDERWRITING PURPOSES.—The term ‘underwriting purposes’ means, with respect to a group health plan, health insurance coverage, or a medicare supplemental policy—

“(A) rules for, or determination of, eligibility (including enrollment and continued eligibility) for, or determination of, benefits under the plan, coverage, or policy;

“(B) the computation of premium or contribution amounts under the plan, coverage, or policy;

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

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

Notice.
Federal Register,
publication.
Deadline.
Effective date.

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

“(d) ENFORCEMENT.—In addition to any other sanctions or remedies that may be available under law, a covered entity that is a group health plan, health insurance issuer, or issuer of a medicare supplemental policy and that violates the HIPAA privacy regulation (as revised under subsection (a) or otherwise) with respect to the use or disclosure of genetic information shall be subject to the

penalties described in sections 1176 and 1177 in the same manner and to the same extent that such penalties apply to violations of this part.”.

(b) REGULATIONS; EFFECTIVE DATE.—

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

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

42 USC
1320d-9 note.
Deadline.

SEC. 106. ASSURING COORDINATION.

Except as provided in section 105(b)(1), the Secretary of Health and Human Services, the Secretary of Labor, and the Secretary of the Treasury shall ensure, through the execution of an inter-agency memorandum of understanding among such Secretaries, that—

(1) regulations, rulings, and interpretations issued by such Secretaries relating to the same matter over which two or more such Secretaries have responsibility under this title (and the amendments made by this title) are administered so as to have the same effect at all times; and

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

Memorandum.
42 USC
300gg-1 note.

TITLE II—PROHIBITING EMPLOYMENT DISCRIMINATION ON THE BASIS OF GENETIC INFORMATION

SEC. 201. DEFINITIONS.

In this title:

(1) COMMISSION.—The term “Commission” means the Equal Employment Opportunity Commission as created by section 705 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-4).

(2) EMPLOYEE; EMPLOYER; EMPLOYMENT AGENCY; LABOR ORGANIZATION; MEMBER.—

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

(i) an employee (including an applicant), as defined in section 701(f) of the Civil Rights Act of 1964 (42 U.S.C. 2000e(f));

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

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

42 USC 2000ff.

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

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

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

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

(ii) an entity employing a State employee described in section 304(a) of the Government Employee Rights Act of 1991;

(iii) an employing office, as defined in section 101 of the Congressional Accountability Act of 1995;

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

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

(C) EMPLOYMENT AGENCY; LABOR ORGANIZATION.—The terms “employment agency” and “labor organization” have the meanings given the terms in section 701 of the Civil Rights Act of 1964 (42 U.S.C. 2000e).

(D) MEMBER.—The term “member”, with respect to a labor organization, includes an applicant for membership in a labor organization.

(3) FAMILY MEMBER.—The term “family member” means, with respect to an individual—

(A) a dependent (as such term is used for purposes of section 701(f)(2) of the Employee Retirement Income Security Act of 1974) of such individual, and

(B) any other individual who is a first-degree, second-degree, third-degree, or fourth-degree relative of such individual or of an individual described in subparagraph (A).

(4) GENETIC INFORMATION.—

(A) IN GENERAL.—The term “genetic information” means, with respect to any individual, information about—

(i) such individual’s genetic tests,

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

(iii) the manifestation of a disease or disorder in family members of such individual.

(B) INCLUSION OF GENETIC SERVICES AND PARTICIPATION IN GENETIC RESEARCH.—Such term includes, with respect to any individual, any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual.

(C) EXCLUSIONS.—The term “genetic information” shall not include information about the sex or age of any individual.

(5) 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.

(6) GENETIC SERVICES.—The term “genetic services” means—

(A) a genetic test;

(B) genetic counseling (including obtaining, interpreting, or assessing genetic information); or

(C) genetic education.

(7) GENETIC TEST.—

(A) IN GENERAL.—The term “genetic test” means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.

(B) EXCEPTIONS.—The term “genetic test” does not mean an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes.

SEC. 202. EMPLOYER PRACTICES.

42 USC 2000ff-1.

(a) DISCRIMINATION BASED ON GENETIC INFORMATION.—It shall be an unlawful employment practice for an employer—

(1) to fail or refuse to hire, or to discharge, any employee, or otherwise to discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of genetic information with respect to the employee; or

(2) to limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee as an employee, because of genetic information with respect to the employee.

(b) ACQUISITION OF GENETIC INFORMATION.—It shall be an unlawful employment practice for an employer to request, require, or purchase genetic information with respect to an employee or a family member of the employee except—

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

(2) where—

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

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

(C) only the employee (or family member if the family member is receiving genetic services) and the licensed health care professional or board certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services; and

(D) any individually identifiable genetic information provided under subparagraph (C) in connection with the services provided under subparagraph (A) is only available for purposes of such services and shall not be disclosed to the employer except in aggregate terms that do not disclose the identity of specific employees;

(3) where an employer requests or requires family medical history from the employee to comply with the certification

provisions of section 103 of the Family and Medical Leave Act of 1993 (29 U.S.C. 2613) or such requirements under State family and medical leave laws;

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

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

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

(B)(i) the employee provides prior, knowing, voluntary, and written authorization; or

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

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

(D) the monitoring is in compliance with—

(i) any Federal genetic monitoring regulations, including any such regulations that may be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.), the Federal Mine Safety and Health Act of 1977 (30 U.S.C. 801 et seq.), or the Atomic Energy Act of 1954 (42 U.S.C. 2011 et seq.); or

(ii) State genetic monitoring regulations, in the case of a State that is implementing genetic monitoring regulations under the authority of the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.); and

(E) the employer, excluding any licensed health care professional or board certified genetic counselor that is involved in the genetic monitoring program, receives the results of the monitoring only in aggregate terms that do not disclose the identity of specific employees; or

(6) where the employer conducts DNA analysis for law enforcement purposes as a forensic laboratory or for purposes of human remains identification, and requests or requires genetic information of such employer's employees, but only to the extent that such genetic information is used for analysis of DNA identification markers for quality control to detect sample contamination.

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

42 USC 2000ff-2.

SEC. 203. EMPLOYMENT AGENCY PRACTICES.

(a) DISCRIMINATION BASED ON GENETIC INFORMATION.—It shall be an unlawful employment practice for an employment agency—

(1) to fail or refuse to refer for employment, or otherwise to discriminate against, any individual because of genetic information with respect to the 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 otherwise adversely affect the status of the individual as an employee, because of genetic information with respect to the individual; or

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

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

(1) where an employment agency inadvertently requests or requires family medical history of the individual or family member of the individual;

(2) where—

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

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

(C) only the individual (or family member if the family member is receiving genetic services) and the licensed health care professional or board certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services; and

(D) any individually identifiable genetic information provided under subparagraph (C) in connection with the services provided under subparagraph (A) is only available for purposes of such services and shall not be disclosed to the employment agency except in aggregate terms that do not disclose the identity of specific individuals;

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

(4) where an employment agency purchases documents that are commercially and publicly available (including newspapers, magazines, periodicals, and books, but not including medical databases or court records) that include family medical history; or

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

(A) the employment agency provides written notice of the genetic monitoring to the individual;

(B)(i) the individual provides prior, knowing, voluntary, and written authorization; or

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

(C) the individual is informed of individual monitoring results;

(D) the monitoring is in compliance with—

(i) any Federal genetic monitoring regulations, including any such regulations that may be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of 1970 (29 U.S.C.

651 et seq.), the Federal Mine Safety and Health Act of 1977 (30 U.S.C. 801 et seq.), or the Atomic Energy Act of 1954 (42 U.S.C. 2011 et seq.); or

(ii) State genetic monitoring regulations, in the case of a State that is implementing genetic monitoring regulations under the authority of the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.); and

(E) the employment agency, excluding any licensed health care professional or board certified genetic counselor that is involved in the genetic monitoring program, receives the results of the monitoring only in aggregate terms that do not disclose the identity of specific individuals.

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

42 USC 2000ff-3.

SEC. 204. LABOR ORGANIZATION PRACTICES.

(a) DISCRIMINATION BASED ON GENETIC INFORMATION.—It shall be an unlawful employment practice for a labor organization—

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

(2) to limit, segregate, or classify the members of the organization, or fail or refuse to refer for employment any member, in any way that would deprive or tend to deprive any member of employment opportunities, or otherwise adversely affect the status of the member as an employee, because of genetic information with respect to the member; or

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

(b) ACQUISITION OF GENETIC INFORMATION.—It shall be an unlawful employment practice for a labor organization to request, require, or purchase genetic information with respect to a member or a family member of the member except—

(1) where a labor organization inadvertently requests or requires family medical history of the member or family member of the member;

(2) where—

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

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

(C) only the member (or family member if the family member is receiving genetic services) and the licensed health care professional or board certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services; and

(D) any individually identifiable genetic information provided under subparagraph (C) in connection with the services provided under subparagraph (A) is only available for purposes of such services and shall not be disclosed

to the labor organization except in aggregate terms that do not disclose the identity of specific members;

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

(4) where a labor organization purchases documents that are commercially and publicly available (including newspapers, magazines, periodicals, and books, but not including medical databases or court records) that include family medical history; or

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

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

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

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

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

(D) the monitoring is in compliance with—

(i) any Federal genetic monitoring regulations, including any such regulations that may be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.), the Federal Mine Safety and Health Act of 1977 (30 U.S.C. 801 et seq.), or the Atomic Energy Act of 1954 (42 U.S.C. 2011 et seq.); or

(ii) State genetic monitoring regulations, in the case of a State that is implementing genetic monitoring regulations under the authority of the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.); and

(E) the labor organization, excluding any licensed health care professional or board certified genetic counselor that is involved in the genetic monitoring program, receives the results of the monitoring only in aggregate terms that do not disclose the identity of specific members.

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

SEC. 205. TRAINING PROGRAMS.

42 USC 2000ff-4.

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

(1) to discriminate against any individual because of genetic information with respect to the individual in admission to, or employment in, any program established to provide apprenticeship or other training or retraining;

(2) to limit, segregate, or classify the applicants for or participants in such apprenticeship or other training or retraining, 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 otherwise adversely affect the status of the individual as an employee, because of genetic information with respect to the individual; or

(3) to cause or attempt to cause an employer to discriminate against an applicant for or a participant in such apprenticeship or other training or retraining in violation of this title.

(b) ACQUISITION OF GENETIC INFORMATION.—It shall be an unlawful employment practice for an employer, labor organization, or joint labor-management committee described in subsection (a) to request, require, or purchase genetic information with respect to an individual or a family member of the individual except—

(1) where the employer, labor organization, or joint labor-management committee inadvertently requests or requires family medical history of the individual or family member of the individual;

(2) where—

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

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

(C) only the individual (or family member if the family member is receiving genetic services) and the licensed health care professional or board certified genetic counselor involved in providing such services receive individually identifiable information concerning the results of such services; and

(D) any individually identifiable genetic information provided under subparagraph (C) in connection with the services provided under subparagraph (A) is only available for purposes of such services and shall not be disclosed to the employer, labor organization, or joint labor-management committee except in aggregate terms that do not disclose the identity of specific individuals;

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

(4) where the employer, labor organization, or joint labor-management committee purchases documents that are commercially and publicly available (including newspapers, magazines, periodicals, and books, but not including medical databases or court records) that include family medical history;

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

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

Notification.

(B)(i) the individual provides prior, knowing, voluntary, and written authorization; or

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

(C) the individual is informed of individual monitoring results;

(D) the monitoring is in compliance with—

(i) any Federal genetic monitoring regulations, including any such regulations that may be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.), the Federal Mine Safety and Health Act of 1977 (30 U.S.C. 801 et seq.), or the Atomic Energy Act of 1954 (42 U.S.C. 2011 et seq.); or

(ii) State genetic monitoring regulations, in the case of a State that is implementing genetic monitoring regulations under the authority of the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.); and

(E) the employer, labor organization, or joint labor-management committee, excluding any licensed health care professional or board certified genetic counselor that is involved in the genetic monitoring program, receives the results of the monitoring only in aggregate terms that do not disclose the identity of specific individuals; or

(6) where the employer conducts DNA analysis for law enforcement purposes as a forensic laboratory or for purposes of human remains identification, and requests or requires genetic information of such employer's apprentices or trainees, but only to the extent that such genetic information is used for analysis of DNA identification markers for quality control to detect sample contamination.

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

SEC. 206. CONFIDENTIALITY OF GENETIC INFORMATION.

42 USC 2000ff-5.

(a) TREATMENT OF INFORMATION AS PART OF CONFIDENTIAL MEDICAL RECORD.—If an employer, employment agency, labor organization, or joint labor-management committee possesses genetic information about an employee or member, such information shall be maintained on separate forms and in separate medical files and be treated as a confidential medical record of the employee or member. An employer, employment agency, labor organization, or joint labor-management committee shall be considered to be in compliance with the maintenance of information requirements of this subsection with respect to genetic information subject to this subsection that is maintained with and treated as a confidential medical record under section 102(d)(3)(B) of the Americans With Disabilities Act (42 U.S.C. 12112(d)(3)(B)).

(b) LIMITATION ON DISCLOSURE.—An employer, employment agency, labor organization, or joint labor-management committee shall not disclose genetic information concerning an employee or member except—

(1) to the employee or member of a labor organization (or family member if the family member is receiving the genetic services) at the written request of the employee or member of such organization;

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

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

(A) the employer, employment agency, labor organization, or joint labor-management committee may disclose only the genetic information expressly authorized by such order; and

(B) if the court order was secured without the knowledge of the employee or member to whom the information refers, the employer, employment agency, labor organization, or joint labor-management committee shall inform the employee or member of the court order and any genetic information that was disclosed pursuant to such order;

(4) to government officials who are investigating compliance with this title if the information is relevant to the investigation;

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

(6) to a Federal, State, or local public health agency only with regard to information that is described in section 201(4)(A)(iii) and that concerns a contagious disease that presents an imminent hazard of death or life-threatening illness, and that the employee whose family member or family members is or are the subject of a disclosure under this paragraph is notified of such disclosure.

(c) RELATIONSHIP TO HIPAA REGULATIONS.—With respect to the regulations promulgated by the Secretary of Health and Human Services under part C of title XI of the Social Security Act (42 U.S.C. 1320d et seq.) and section 264 of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d-2 note), this title does not prohibit a covered entity under such regulations from any use or disclosure of health information that is authorized for the covered entity under such regulations. The previous sentence does not affect the authority of such Secretary to modify such regulations.

42 USC 2000ff-6.

SEC. 207. REMEDIES AND ENFORCEMENT.

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

(1) IN GENERAL.—The powers, procedures, and remedies provided in sections 705, 706, 707, 709, 710, and 711 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-4 et seq.) to the Commission, the Attorney General, or any person, alleging a violation of title VII of that Act (42 U.S.C. 2000e et seq.) shall be the powers, procedures, and remedies this title provides to the Commission, the Attorney General, or any person, respectively, alleging an unlawful employment practice in violation of this title against an employee described in section 201(2)(A)(i), except as provided in paragraphs (2) and (3).

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

(3) DAMAGES.—The powers, remedies, and procedures provided in section 1977A of the Revised Statutes of the United States (42 U.S.C. 1981a), including the limitations contained in subsection (b)(3) of such section 1977A, shall be powers, remedies, and procedures this title provides to the Commission, the Attorney General, or any person, alleging such a practice (not an employment practice specifically excluded from coverage under section 1977A(a)(1) of the Revised Statutes of the United States).

(b) EMPLOYEES COVERED BY GOVERNMENT EMPLOYEE RIGHTS ACT OF 1991.—

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

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

(3) DAMAGES.—The powers, remedies, and procedures provided in section 1977A of the Revised Statutes of the United States (42 U.S.C. 1981a), including the limitations contained in subsection (b)(3) of such section 1977A, shall be powers, remedies, and procedures this title provides to the Commission, or any person, alleging such a practice (not an employment practice specifically excluded from coverage under section 1977A(a)(1) of the Revised Statutes of the United States).

(c) EMPLOYEES COVERED BY CONGRESSIONAL ACCOUNTABILITY ACT OF 1995.—

(1) IN GENERAL.—The powers, remedies, and procedures provided in the Congressional Accountability Act of 1995 (2 U.S.C. 1301 et seq.) to the Board (as defined in section 101 of that Act (2 U.S.C. 1301)), or any person, alleging a violation of section 201(a)(1) of that Act (42 U.S.C. 1311(a)(1)) shall be the powers, remedies, and procedures this title provides to that Board, or any person, alleging an unlawful employment practice in violation of this title against an employee described in section 201(2)(A)(iii), except as provided in paragraphs (2) and (3).

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

(3) DAMAGES.—The powers, remedies, and procedures provided in section 1977A of the Revised Statutes of the United States (42 U.S.C. 1981a), including the limitations contained in subsection (b)(3) of such section 1977A, shall be powers, remedies, and procedures this title provides to that Board, or any person, alleging such a practice (not an employment practice specifically excluded from coverage under section 1977A(a)(1) of the Revised Statutes of the United States).

(4) OTHER APPLICABLE PROVISIONS.—With respect to a claim alleging a practice described in paragraph (1), title III of the Congressional Accountability Act of 1995 (2 U.S.C. 1381 et seq.) shall apply in the same manner as such title applies with respect to a claim alleging a violation of section 201(a)(1) of such Act (2 U.S.C. 1311(a)(1)).

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

(1) IN GENERAL.—The powers, remedies, and procedures provided in chapter 5 of title 3, United States Code, to the President, the Commission, the Merit Systems Protection Board, or any person, alleging a violation of section 411(a)(1) of that title, shall be the powers, remedies, and procedures this title provides to the President, the Commission, such Board, or any person, respectively, alleging an unlawful employment practice in violation of this title against an employee described in section 201(2)(A)(iv), except as provided in paragraphs (2) and (3).

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

(3) DAMAGES.—The powers, remedies, and procedures provided in section 1977A of the Revised Statutes of the United States (42 U.S.C. 1981a), including the limitations contained in subsection (b)(3) of such section 1977A, shall be powers, remedies, and procedures this title provides to the President, the Commission, such Board, or any person, alleging such a practice (not an employment practice specifically excluded from coverage under section 1977A(a)(1) of the Revised Statutes of the United States).

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

(1) IN GENERAL.—The powers, remedies, and procedures provided in section 717 of the Civil Rights Act of 1964 (42 U.S.C. 2000e-16) to the Commission, the Attorney General, the Librarian of Congress, or any person, alleging a violation of that section shall be the powers, remedies, and procedures this title provides to the Commission, the Attorney General, the Librarian of Congress, or any person, respectively, alleging an unlawful employment practice in violation of this title against an employee or applicant described in section 201(2)(A)(v), except as provided in paragraphs (2) and (3).

(2) COSTS AND FEES.—The powers, remedies, and procedures provided in subsections (b) and (c) of section 722 of the Revised Statutes of the United States (42 U.S.C. 1988), shall be powers, remedies, and procedures this title provides

to the Commission, the Attorney General, the Librarian of Congress, or any person, alleging such a practice.

(3) DAMAGES.—The powers, remedies, and procedures provided in section 1977A of the Revised Statutes of the United States (42 U.S.C. 1981a), including the limitations contained in subsection (b)(3) of such section 1977A, shall be powers, remedies, and procedures this title provides to the Commission, the Attorney General, the Librarian of Congress, or any person, alleging such a practice (not an employment practice specifically excluded from coverage under section 1977A(a)(1) of the Revised Statutes of the United States).

(f) PROHIBITION AGAINST RETALIATION.—No person shall discriminate against any individual because such individual has opposed any act or practice made unlawful by this title or because such individual made a charge, testified, assisted, or participated in any manner in an investigation, proceeding, or hearing under this title. The remedies and procedures otherwise provided for under this section shall be available to aggrieved individuals with respect to violations of this subsection.

(g) DEFINITION.—In this section, the term “Commission” means the Equal Employment Opportunity Commission.

SEC. 208. DISPARATE IMPACT.

42 USC 2000ff-7.

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

(b) COMMISSION.—On the date that is 6 years after the date of enactment of this Act, there shall be established a commission, to be known as the Genetic Nondiscrimination Study Commission (referred to in this section as the “Commission”) to review the developing science of genetics and to make recommendations to Congress regarding whether to provide a disparate impact cause of action under this Act.

Effective date.
Establishment.

(c) MEMBERSHIP.—

(1) IN GENERAL.—The Commission shall be composed of 8 members, of which—

(A) 1 member shall be appointed by the Majority Leader of the Senate;

(B) 1 member shall be appointed by the Minority Leader of the Senate;

(C) 1 member shall be appointed by the Chairman of the Committee on Health, Education, Labor, and Pensions of the Senate;

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

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

(F) 1 member shall be appointed by the Minority Leader of the House of Representatives;

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

(H) 1 member shall be appointed by the ranking minority member of the Committee on Education and Labor of the House of Representatives.

(2) COMPENSATION AND EXPENSES.—The members of the Commission shall not receive compensation for the performance of services for the Commission, but shall be allowed travel expenses, including per diem in lieu of subsistence, at rates authorized for employees of agencies under subchapter I of chapter 57 of title 5, United States Code, while away from their homes or regular places of business in the performance of services for the Commission.

(d) ADMINISTRATIVE PROVISIONS.—

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

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

(3) INFORMATION FROM FEDERAL AGENCIES.—The Commission may secure directly from any Federal department or agency such information as the Commission considers necessary to carry out the provisions of this section. Upon request of the Commission, the head of such department or agency shall furnish such information to the Commission.

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

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

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

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

42 USC 2000ff-8.

SEC. 209. CONSTRUCTION.

(a) IN GENERAL.—Nothing in this title shall be construed to—

(1) limit the rights or protections of an individual under any other Federal or State statute that provides equal or greater protection to an individual than the rights or protections provided for under this title, including the protections of an individual under the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.) (including coverage afforded to individuals under section 102 of such Act (42 U.S.C. 12112)), or under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.);

(2)(A) limit the rights or protections of an individual to bring an action under this title against an employer, employment agency, labor organization, or joint labor-management committee for a violation of this title; or

(B) provide for enforcement of, or penalties for violation of, any requirement or prohibition applicable to any employer, employment agency, labor organization, or joint labor-management committee subject to enforcement for a violation under—

Applicability.

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

(ii)(I) subsection (a) of section 701 of the Employee Retirement Income Security Act of 1974 as such section applies with respect to genetic information pursuant to subsection (b)(1)(B) of such section;

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

(III) section 702(b)(1) of such Act as such section applies with respect to genetic information as a health status-related factor;

(iii)(I) subsection (a) of section 2701 of the Public Health Service Act as such section applies with respect to genetic information pursuant to subsection (b)(1)(B) of such section;

(II) section 2702(a)(1)(F) of such Act; or

(III) section 2702(b)(1) of such Act as such section applies with respect to genetic information as a health status-related factor; or

(iv)(I) subsection (a) of section 9801 of the Internal Revenue Code of 1986 as such section applies with respect to genetic information pursuant to subsection (b)(1)(B) of such section;

(II) section 9802(a)(1)(F) of such Act; or

(III) section 9802(b)(1) of such Act as such section applies with respect to genetic information as a health status-related factor;

(3) apply to the Armed Forces Repository of Specimen Samples for the Identification of Remains;

(4) limit or expand the protections, rights, or obligations of employees or employers under applicable workers' compensation laws;

(5) limit the authority of a Federal department or agency to conduct or sponsor occupational or other health research that is conducted in compliance with the regulations contained in part 46 of title 45, Code of Federal Regulations (or any corresponding or similar regulation or rule);

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

(7) require any specific benefit for an employee or member or a family member of an employee or member under any group health plan or health insurance issuer offering group health insurance coverage in connection with a group health plan.

(b) GENETIC INFORMATION OF A FETUS OR EMBRYO.—Any reference in this title to genetic information concerning an individual or family member of an individual shall—

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

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

(c) **RELATION TO AUTHORITIES UNDER TITLE I.**—With respect to a group health plan, or a health insurance issuer offering group health insurance coverage in connection with a group health plan, this title does not prohibit any activity of such plan or issuer that is authorized for the plan or issuer under any provision of law referred to in clauses (i) through (iv) of subsection (a)(2)(B).

42 USC 2000ff–9. **SEC. 210. MEDICAL INFORMATION THAT IS NOT GENETIC INFORMATION.**

An employer, employment agency, labor organization, or joint labor-management committee shall not be considered to be in violation of this title based on the use, acquisition, or disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition of an employee or member, including a manifested disease, disorder, or pathological condition that has or may have a genetic basis.

Deadline.
42 USC
2000ff–10. **SEC. 211. REGULATIONS.**

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

42 USC
2000ff–11. **SEC. 212. AUTHORIZATION OF APPROPRIATIONS.**

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

42 USC 2000ff
note. **SEC. 213. EFFECTIVE DATE.**

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

TITLE III—MISCELLANEOUS PROVISIONS

42 USC 2000ff
note. **SEC. 301. SEVERABILITY.**

If any provision of this Act, an amendment made by this Act, or the application of such provision or amendment to any person or circumstance is held to be unconstitutional, the remainder of this Act, the amendments made by this Act, and the application of such provisions to any person or circumstance shall not be affected thereby.

SEC. 302. CHILD LABOR PROTECTIONS.

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

Penalties. “(e)(1)(A) Any person who violates the provisions of sections 12 or 13(c), relating to child labor, or any regulation issued pursuant to such sections, shall be subject to a civil penalty not to exceed—

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

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

“(B) For purposes of subparagraph (A), the term ‘serious injury’ means—

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

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

“(iii) permanent paralysis or substantial impairment that causes loss of movement or mobility of an arm, leg, foot, hand or other body part.

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

“(3) In determining the amount of any penalty under this subsection, the appropriateness of such penalty to the size of the business of the person charged and the gravity of the violation shall be considered. The amount of any penalty under this subsection, when finally determined, may be—

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

“(B) recovered in a civil action brought by the Secretary in any court of competent jurisdiction, in which litigation the Secretary shall be represented by the Solicitor of Labor; or

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

“(4) Any administrative determination by the Secretary of the amount of any penalty under this subsection shall be final, unless within 15 days after receipt of notice thereof by certified mail the person charged with the violation takes exception to the determination that the violations for which the penalty is imposed occurred, in which event final determination of the penalty shall be made in an administrative proceeding after opportunity for hearing in accordance with section 554 of title 5, United States Code, and regulations to be promulgated by the Secretary.

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

Deadline.
Notification.
Regulations.

29 USC 216 note. (b) EFFECTIVE DATE.—The amendments made by this section shall take effect on the date of the enactment of this Act.

Approved May 21, 2008.

LEGISLATIVE HISTORY—H.R. 493 (S. 358):

HOUSE REPORTS: No. 110–28, Pt. 1 (Comm. on Education and Labor), Pt. 2 (Comm. on Ways and Means), and Pts. 3 and 4 (Comm. on Energy and Commerce).

SENATE REPORTS: No. 110–48 accompanying S. 358 (Comm. on Health, Education, Labor, and Pensions).

CONGRESSIONAL RECORD:

Vol. 153 (2007): Apr. 25, considered and passed House.

Vol. 154 (2008): Apr. 24, considered and passed Senate, amended.

May 1, House concurred in Senate amendment.

WEEKLY COMPILATION OF PRESIDENTIAL DOCUMENTS, Vol. 44 (2008):

May 21, Presidential remarks.

