AN ACT

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

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

3 SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Genetic Information Nondiscrimination Act of 2003”.
(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. 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.
Sec. 107. Regulations; effective date.

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

Sec. 201. Definitions.
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 PROVISION

Sec. 301. Severability.

3 SEC. 2. FINDINGS.

4 Congress makes the following findings:

5 (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 con-
tract a particular disorder. New knowledge about ge-
etics may allow for the development of better therap-
ies 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 ge-
etic traits or tendencies. Many of these State laws
have since been repealed, and many have been modi-
fied 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 NON-DISCRIMINATION IN HEALTH INSURANCE

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

(a) Prohibition of Health Discrimination on the Basis of Genetic Information or Genetic Services.—

(1) No enrollment restriction for genetic services.—Section 702(a)(1)(F) of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1182(a)(1)(F)) is amended by inserting before the period the following: “(including information about a request for or receipt of genetic services by an individual or family member of such individual)”.

(2) 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—

(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 DISCRIMINATION IN GROUP PREMIUMS BASED ON GENETIC INFORMATION.—For purposes of this section, a group health plan, or a health insurance issuer offering group health insurance coverage in connection with a group health plan, shall not adjust premium or contribution amounts for a group on the basis of genetic information concerning an individual in the group or a family member of the individual (including information about a request for or receipt of genetic services by an individual or family member of such individual).”.

(b) LIMITATIONS ON GENETIC TESTING.—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, or a health insurance issuer offering health insurance coverage in connection with a group health plan, shall not request or require an individual or a family member of such individual to undergo a genetic test.

“(2) RULE OF CONSTRUCTION.—Nothing in this part shall be construed to—
“(A) limit the authority of a health care professional who is providing health care services with respect to an individual to request that such individual or a family member of such individual undergo a genetic test;

“(B) limit the authority of a health care professional who is employed by or affiliated with a group health plan or a health insurance issuer and who is providing health care services to an individual as part of a bona fide wellness program to notify such individual of the availability of a genetic test or to provide information to such individual regarding such genetic test; or

“(C) authorize or permit a health care professional to require that an individual undergo a genetic test.

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

(c) REMEDIES AND ENFORCEMENT.—Section 502 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1132) is amended by adding at the end the following:
“(n) Enforcement of Genetic Nondiscrimination Requirements.—

“(1) Injunctive Relief for Irreparable Harm.—With respect to any violation of subsection (a)(1)(F), (b)(3), or (c) of section 702, a participant or beneficiary may seek relief under subsection 502(a)(1)(B) prior to the exhaustion of available administrative remedies under section 503 if it is demonstrated to the court, by a preponderance of the evidence, that the exhaustion of such remedies would cause irreparable harm to the health of the participant or beneficiary. Any determinations that already have been made under section 503 in such case, or that are made in such case while an action under this paragraph is pending, shall be given due consideration by the court in any action under this subsection in such case.

“(2) Equitable Relief for Genetic Nondiscrimination.—

“(A) Reinstatement of Benefits Where Equitable Relief Has Been Awarded.—The recovery of benefits by a participant or beneficiary under a civil action under this section may include an administrative penalty under subparagraph (B) and the retroactive re-
instatement of coverage under the plan involved
to the date on which the participant or bene-

ficiary was denied eligibility for coverage if—

“(i) the civil action was commenced
under subsection (a)(1)(B); and

“(ii) the denial of coverage on which
such civil action was based constitutes a
violation of subsection (a)(1)(F), (b)(3), or
(c) of section 702.

“(B) ADMINISTRATIVE PENALTY.—

“(i) IN GENERAL.—An administrator
who fails to comply with the requirements
of subsection (a)(1)(F), (b)(3), or (c) of
section 702 with respect to a participant or
beneficiary may, in an action commenced
under subsection (a)(1)(B), be personally
liable in the discretion of the court, for a
penalty in the amount not more than $100
for each day in the noncompliance period.

“(ii) NONCOMPLIANCE PERIOD.—For
purposes of clause (i), the term ‘non-
compliance period’ means the period—

“(I) beginning on the date that a
failure described in clause (i) occurs;

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

“(iii) Payment to Participant or Beneficiary.—A penalty collected under this subparagraph shall be paid to the participant or beneficiary involved.

“(3) Secretarial Enforcement Authority.—

“(A) General Rule.—The Secretary has the authority to impose a penalty on any failure of a group health plan to meet the requirements of subsection (a)(1)(F), (b)(3), or (c) of section 702.

“(B) Amount.—

“(i) In general.—The amount of the penalty imposed by subparagraph (A) shall be $100 for each day in the non-compliance period with respect to each individual to whom such failure relates.

“(ii) Noncompliance Period.—For purposes of this paragraph, the term ‘non-compliance period’ means, with respect to any failure, the period—

“(I) beginning on the date such failure first occurs; and
“(II) ending on the date such 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 sub-
stituting ‘$15,000’ for ‘$2,500’ with re-
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 exer-
cising 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 rea-
sonable cause and not to willful ne-
glect; and

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

“(iii) OVERALL LIMITATION FOR UN-
INTENTIONAL FAILURES.—In the case of
failures which are due to reasonable cause
and not to willful neglect, the penalty im-
posed 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 em-
ployer (or predecessor employer) dur-
ing 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 sub-
paragraph (A) to the extent that the payment
of such penalty would be excessive relative to
the failure involved.”.

(d) DEFINITIONS.—Section 733(d) of the Employee
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) the spouse of the individual;

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

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

“(6) GENETIC INFORMATION.—

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

“(i) an individual’s genetic tests;

“(ii) the genetic tests of family members of the individual; or

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

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

“(7) GENETIC TEST.—

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

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

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

“(ii) an analysis of proteins or me-
tabolites that is directly related to a mani-
fested disease, disorder, or pathological
condition that could reasonably be detected
by a health care professional with appro-
priate training and expertise in the field of
medicine involved.

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

“(A) a genetic test;

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

“(C) genetic education.”.

(e) REGULATIONS AND EFFECTIVE DATE.—

(1) REGULATIONS.—Not later than 1 year after
the date of enactment of this title, the Secretary of
Labor shall issue final regulations in an accessible format 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 18 months after the date of enactment of this title.

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

(a) Amendments Relating to the Group Market.—

(1) Prohibition of health discrimination on the basis of genetic information or genetic services.—

(A) No enrollment restriction for genetic services.—Section 2702(a)(1)(F) of the Public Health Service Act (42 U.S.C. 300gg–1(a)(1)(F)) is amended by inserting before the period the following: “(including information about a request for or receipt of genetic services by an individual or family member of such individual)”.

(B) 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—

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

(ii) by adding at the end the following:

“(3) NO DISCRIMINATION IN GROUP PREMIUMS BASED ON GENETIC INFORMATION.—For purposes of this section, a group health plan, or a health insurance issuer offering group health insurance coverage in connection with a group health plan, shall not adjust premium or contribution amounts for a group on the basis of genetic information concerning an individual in the group or a family member of the individual (including information about a request for or receipt of genetic services by an individual or family member of such individual).”.

(2) LIMITATIONS ON GENETIC TESTING.—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, or a
health insurance issuer offering health insurance
coverage in connection with a group health plan,
shall not request or require an individual or a family
member of such individual to undergo a genetic test.

“(2) RULE OF CONSTRUCTION.—Nothing in
this part shall be construed to—

“(A) limit the authority of a health care
professional who is providing health care serv-
ices with respect to an individual to request
that such individual or a family member of such
individual undergo a genetic test;

“(B) limit the authority of a health care
professional who is employed by or affiliated
with a group health plan or a health insurance
issuer and who is providing health care services
to an individual as part of a bona fide wellness
program to notify such individual of the avail-
ability of a genetic test or to provide informa-
tion to such individual regarding such genetic
test; or

“(C) authorize or permit a health care pro-
fessional to require that an individual undergo
a genetic test.

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

(3) 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 following provisions 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), or (c) of section 2702.

“(B) Amount.—

“(i) In general.—The amount of the penalty imposed under this paragraph shall be $100 for each day in the non-compliance period with respect to each individual to whom such failure relates.

“(ii) Noncompliance period.—For purposes of this paragraph, the term ‘non-
compliance period’ means, with respect to any failure, the period—

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

“(II) ending on the date such 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 para-
graph for any year are more than de mini-
mis, clause (i) shall be applied by sub-
stituting ‘$15,000’ for ‘$2,500’ with re-
spect to such person.

“(D) LIMITATIONS.—

“(i) Penalty not to apply where
failure not discovered exercising reasona-
ble 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 exer-
cising reasonable diligence would not have
known, that such failure existed.

“(ii) Penalty not to apply to fail-
ures corrected within certain peri-
odns.—No penalty shall be imposed by sub-
paragraph (A) on any failure if—

“(I) such failure was due to rea-
sonable cause and not to willful ne-
glect; and

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

“(iii) OVERALL LIMITATION FOR UN-
INTENTIONAL FAILURES.—In the case of
failures which are due to reasonable cause
and not to willful neglect, the penalty im-
posed 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 em-
ployer (or predecessor employer) dur-
ing 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 sub-
paragraph (A) to the extent that the payment
of such penalty would be excessive relative to
the failure involved.”.
(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 an individual—

“(A) the spouse of the individual;

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

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

“(16) GENETIC INFORMATION.—

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

“(i) an individual’s genetic tests;

“(ii) the genetic tests of family members of the individual; or

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

“(B) EXCLUSIONS.—The term ‘genetic information’ shall not include information about the sex or age of an 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 (such as obtaining, interpreting, or assessing genetic information); or

“(C) genetic education.”.
(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.

“(a) Prohibition on Genetic Information as a Condition of Eligibility.—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 (including information about a request for or receipt of genetic services by an individual or family member of such individual).

“(b) Prohibition on Genetic Information in Setting Premium Rates.—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 (includ-
ing information about a request for or receipt of genetic
services by an individual or family member of such
individual).

“(c) 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.—Nothing in this part shall be construed to—

“(A) limit the authority of a health care professional who is providing health care services with respect to an individual to request that such individual or a family member of such individual undergo a genetic test;

“(B) limit the authority of a health care professional who is employed by or affiliated with a health insurance issuer and who is providing health care services to an individual as part of a bona fide wellness program to notify such individual of the availability of a genetic
test or to provide information to such individual regarding such genetic test; or

“(C) authorize or permit a health care professional to require that an individual undergo a genetic test.”.

(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) and (e) of section 2702 and the provisions of section 2702(b) to the extent that such provisions apply to genetic information (or information about a request for or the receipt of genetic services by an individual or a family member of such individual).”.

(d) REGULATIONS AND EFFECTIVE DATE.—

(1) REGULATIONS.—Not later than 1 year after the date of enactment of this title, the Secretary of Labor and the Secretary of Health and Human Services (as the case may be) shall issue final regulations in an accessible format to carry out the amendments made by this section.

(2) EFFECTIVE DATE.—The amendments made by this section shall apply—
(A) with respect to group health plans, and
health insurance coverage offered in connection
with group health plans, for plan years begin-
ing after the date that is 18 months after the
date of enactment of this title; and

(B) with respect to health insurance cov-
erage offered, sold, issued, renewed, in effect, or
operated in the individual market after the date
that is 18 months after the date of enactment
of this title.

SEC. 103. AMENDMENTS TO THE INTERNAL REVENUE CODE

OF 1986.

(a) Prohibition of Health Discrimination on
the Basis of Genetic Information or Genetic
Services.—

(1) No enrollment restriction for ge-
netic services.—Section 9802(a)(1)(F) of the In-
ternal Revenue Code of 1986 is amended by insert-
ing before the period the following: “(including in-
formation about a request for or receipt of genetic
services by an individual or family member of such
individual)”.

(2) No discrimination in group premiums
based on genetic information.—Section
9802(b) of the Internal Revenue Code of 1986 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 discrimination in group premiums based on genetic information.—For purposes of this section, a group health plan shall not adjust premium or contribution amounts for a group on the basis of genetic information concerning an individual in the group or a family member of the individual (including information about a request for or receipt of genetic services by an individual or family member of such individual).”.

(b) Limitations on Genetic Testing.—Section 9802(b) of the Internal Revenue Code of 1986 is amended by adding at the end the following:

“(d) Genetic Testing and Genetic Services.—

“(1) Limitation on requesting or requiring genetic testing.—A group health plan shall not request or require an individual or a family member of such individual to undergo a genetic test.

“(2) Rule of construction.—Nothing in this part shall be construed to—
“(A) limit the authority of a health care professional who is providing health care services with respect to an individual to request that such individual or a family member of such individual undergo a genetic test;

“(B) limit the authority of a health care professional who is employed by or affiliated with a group health plan and who is providing health care services to an individual as part of a bona fide wellness program to notify such individual of the availability of a genetic test or to provide information to such individual regarding such genetic test; or

“(C) authorize or permit a health care professional to require that an individual undergo a genetic test.

“(e) APPLICATION TO ALL PLANS.—The provisions of subsections (a)(1)(F), (b)(3), and (d) shall apply to group health plans and health insurance issuers without regard to section 9831(a)(2).”.

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

“(6) FAMILY MEMBER.—The term ‘family member’ means with respect to an individual—
“(A) the spouse of the individual;

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

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

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

“(A) a genetic test;

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

“(C) genetic education.

“(8) GENETIC INFORMATION.—

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

“(i) an individual’s genetic tests;

“(ii) the genetic tests of family members of the individual; or

“(iii) the occurrence of a disease or disorder in family members of the individual.
“(B) EXCLUSIONS.—The term ‘genetic information’ shall not include information about the sex or age of an individual.

“(9) 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.”.

(d) REGULATIONS AND EFFECTIVE DATE.—

(1) REGULATIONS.—Not later than 1 year after the date of enactment of this title, the Secretary of the Treasury shall issue final regulations in an ac-
cessible format 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 18 months after the date of enactment of
this title.

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

(a) NONDISCRIMINATION.—

(1) IN GENERAL.—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)(i) An issuer of a medicare supple-
mental policy shall not deny or condition the
issuance or effectiveness of the policy, and shall
not discriminate in the pricing of the policy (in-
cluding the adjustment of premium rates) of an
eligible individual on the basis of genetic infor-
mation concerning the individual (or informa-
tion about a request for, or the receipt of, ge-
etic services by such individual or family mem-
ber of such individual).

“(ii) For purposes of clause (i), the terms
‘family member’, ‘genetic services’, and ‘genetic
information’ shall have the meanings given such terms in subsection (v).”.

(2) EFFECTIVE DATE.—The amendment made by paragraph (1) shall apply with respect to a policy for policy years beginning after the date that is 18 months after the date of enactment of this Act.

(b) LIMITATIONS ON GENETIC TESTING.—

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

“(v) LIMITATIONS ON GENETIC TESTING.—

“(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.—Nothing in this title shall be construed to—

“(i) limit the authority of a health care professional who is providing health care services with respect to an individual to request that such individual or a family member of such individual undergo a genetic test;
“(ii) limit the authority of a health care professional who is employed by or af-
filiated with an issuer of a medicare sup-
plemental policy and who is providing
health care services to an individual as
part of a bona fide wellness program to no-
tify such individual of the availability of a
genetic test or to provide information to
such individual regarding such genetic test;
or
“(iii) authorize or permit a health care professional to require that an indi-
vidual undergo a genetic test.

“(2) DEFINITIONS.—In this subsection:

“(A) FAMILY MEMBER.—The term ‘family member’ means with respect to an individual—
“(i) the spouse of the individual;
“(ii) a dependent child of the indi-
vidual, including a child who is born to or
placed for adoption with the individual; or
“(iii) any other individuals related by
blood to the individual or to the spouse or
child described in clause (i) or (ii).

“(B) GENETIC INFORMATION.—
“(i) IN GENERAL.—Except as provided in clause (ii), the term ‘genetic information’ means information about—

“(I) an individual’s genetic tests;

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

“(III) the occurrence of a disease or disorder in family members of the individual.

“(ii) EXCLUSIONS.—The term ‘genetic information’ shall not include information about the sex or age of an 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 (such as obtaining, interpreting, or assessing genetic information); or

“(iii) genetic education.

“(E) 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) 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 (v).”.

(3) EFFECTIVE DATE.—The amendments made by this subsection shall apply with respect to an issuer of a medicare supplemental policy for policy years beginning on or after the date that is 18 months after the date of enactment of this Act.

(e) TRANSITION PROVISIONS.—

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

(2) NAIC STANDARDS.—If, not later than June 30, 2004, 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 regula-
tion (including the revised NAIC model regulation
and the 1991 NAIC Model Regulation) for the pur-
poses of such section.

(3) SECRETARY STANDARDS.—If the NAIC
does not make the modifications described in para-
graph (2) within the period specified in such para-
graph, the Secretary of Health and Human Services
shall, not later than October 1, 2004, make the
modifications described in such paragraph and such
revised regulation incorporating the modifications
shall be considered to be the appropriate regulation
for the purposes of such section.

(4) DATE SPECIFIED.—

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

(i) the date the State changes its stat-
utes or regulations to conform its regu-
lar program to the changes made by
this section, or

(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 2004 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, 2004. 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) APPLICABILITY.—Except as provided in subsection (d), the provisions of this section shall apply to group health plans, health insurance issuers (including issuers in connection with group health plans or individual
health coverage), and issuers of medicare supplemental policies, without regard to—

(1) section 732(a) of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1191a(a));

(2) section 2721(a) of the Public Health Service Act (42 U.S.C. 300gg–21(a)); and

(3) section 9831(a)(2) of the Internal Revenue Code of 1986.

(b) COMPLIANCE WITH CERTAIN CONFIDENTIALITY STANDARDS WITH RESPECT TO GENETIC INFORMATION.—

(1) IN GENERAL.—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) shall apply to the use or disclosure of genetic information.

(2) PROHIBITION ON UNDERWRITING AND PREMIUM RATING.—Notwithstanding paragraph (1), a group health plan, a health insurance issuer, or issuer of a medicare supplemental policy shall not use or disclose genetic information (including information about a request for or a receipt of genetic services by an individual or family member of such
individual) for purposes of underwriting, determina-
tions of eligibility to enroll, premium rating, or the
creation, renewal or replacement of a plan, contract
or coverage for health insurance or health benefits.

(c) Prohibition on Collection of Genetic In-
formation.—

(1) In general.—A group health plan, health
insurance issuer, or issuer of a medicare supple-
mental policy shall not request, require, or purchase
genetic information (including information about a
request for or a receipt of genetic services by an in-
dividual or family member of such individual) for
purposes of underwriting, determinations of eligi-
bility to enroll, premium rating, or the creation, re-
newal or replacement of a plan, contract or coverage
for health insurance or health benefits.

(2) Limitation relating to the collec-
tion of genetic information prior to enroll-
ment.—A group health plan, health insurance
issuer, or issuer of a medicare supplemental policy
shall not request, require, or purchase genetic infor-
mation (including information about a request for or
a receipt of genetic services by an individual or fam-
ily member of such individual) concerning a partici-
pant, beneficiary, or enrollee prior to the enrollment,
and in connection with such enrollment, of such individual under the plan, coverage, or policy.

(3) INCIDENTAL COLLECTION.—Where a group health plan, health insurance issuer, or issuer of a medicare supplemental policy obtains genetic information incidental to the requesting, requiring, or purchasing of other information concerning a participant, beneficiary, or enrollee, such request, requirement, or purchase shall not be considered a violation of this subsection if—

(A) such request, requirement, or purchase is not in violation of paragraph (1); and

(B) any genetic information (including information about a request for or receipt of genetic services) requested, required, or purchased is not used or disclosed in violation of subsection (b).

(d) APPLICATION OF CONFIDENTIALITY STANDARDS.—The provisions of subsections (b) and (c) shall not apply—

(1) to group health plans, health insurance issuers, or issuers of medicare supplemental policies that are not otherwise covered under the regulations promulgated by the Secretary of Health and Human Services under part C of title XI of the Social Secu-
rity Act (42 U.S.C. 1320d et seq.) and section 264 of the Health Insurance Portability and Account-
ability Act of 1996 (42 U.S.C. 1320d–2 note); and

(2) to genetic information that is not considered to be individually-identifiable health information under 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 Port-

(e) ENFORCEMENT.—A group health plan, health ins-
surance issuer, or issuer of a medicare supplemental policy that violates a provision of this section shall be subject to the penalties described in sections 1176 and 1177 of the Social Security Act (42 U.S.C. 1320d–5 and 1320d–6) in the same manner and to the same extent that such penalties apply to violations of part C of title XI of such Act.

(f) PREEMPTION.—

(1) IN GENERAL.—A provision or requirement under this section or a regulation promulgated under this section shall supersede any contrary provision of State law unless such provision of State law imposes requirements, standards, or implementation speci-
fications that are more stringent than the require-
ments, standards, or implementation specifications
imposed under this section or such regulations. No
penalty, remedy, or cause of action to enforce such
a State law that is more stringent shall be pre-
empted by this section.

(2) Rule of Construction.—Nothing in
paragraph (1) shall be construed to establish a pen-
alty, remedy, or cause of action under State law if
such penalty, remedy, or cause of action is not oth-
erwise available under such State law.

(g) Coordination with Privacy Regulations.—
The Secretary shall implement and administer this section
in a manner that is consistent with the implementation
and administration by the Secretary of the regulations
promulgated by the Secretary of Health and Human Serv-
dices 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

(h) Definitions.—In this section:

(1) Genetic information; genetic serv-
dices.—The terms “family member”, “genetic infor-
mation”, “genetic services”, and “genetic test” have
the meanings given such terms in section 2791 of
the Public Health Service Act (42 U.S.C. 300gg–91), as amended by this Act.

(2) GROUP HEALTH PLAN; HEALTH INSURANCE ISSUER.—The terms “group health plan” and “health insurance issuer” include only those plans and issuers that are covered under the regulations described in subsection (d)(1).

(3) ISSUER OF A MEDICARE SUPPLEMENTAL POLICY.—The term “issuer of a medicare supplemental policy” means an issuer described in section 1882 of the Social Security Act (42 insert 1395ss).

(4) SECRETARY.—The term “Secretary” means the Secretary of Health and Human Services.

SEC. 106. ASSURING COORDINATION.

(a) IN GENERAL.—Except as provided in subsection (b), the Secretary of the Treasury, the Secretary of Health and Human Services, and the Secretary of Labor shall ensure, through the execution of an interagency 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.

(b) Authority of the Secretary.—The Secretary of Health and Human Services has the sole authority to promulgate regulations to implement section 105.

SEC. 107. REGULATIONS; EFFECTIVE DATE.

(a) Regulations.—Not later than 1 year after the date of enactment of this title, the Secretary of Labor, the Secretary of Health and Human Services, and the Secretary of the Treasury shall issue final regulations in an accessible format to carry out this title.

(b) Effective Date.—Except as provided in section 104, the amendments made by this title shall take effect on the date that is 18 months after the date of enactment of this Act.

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

SEC. 201. DEFINITIONS.

In this title:

(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);

   (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) the spouse of the individual;

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

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

(4) GENETIC INFORMATION.—

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

(i) an individual’s genetic tests;

(ii) the genetic tests of family members of the individual; or

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

(B) EXCEPTIONS.—The term “genetic information” shall not include information about the sex or age of an 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 (such as obtaining, interpreting or assessing genetic information); or

(C) genetic education.

(7) Genetic Test.—

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

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

SEC. 202. EMPLOYER PRACTICES.

(a) USE OF 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 information about a request for or the receipt of genetic services by such employee or family member of such 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 (or information about a request for or the receipt of genetic services by such employee or family member of such 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 em-
ployee (or information about a request for the receipt of
genetic services by such employee or a family member of
such 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 bona fide 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 serv-
ices) and the licensed health care professional
or board certified genetic counselor involved in
providing such services receive individually iden-
tifiable information concerning the results of
such services; and

(D) any individually identifiable genetic in-
formation 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; 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 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;

(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) or (2) of subsection (a)
or treated or disclosed in a manner that violates section 206.

SEC. 203. EMPLOYMENT AGENCY PRACTICES.

(a) Use of 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 (or information about a request for or the receipt of genetic services by such individual or family member of such individual);

(2) to limit, segregate, or classify individuals or fail or refuse to refer for employment any individual in any way that would deprive or tend to deprive any individual of employment opportunities, or otherwise adversely affect the status of the individual as an employee, because of genetic information with respect to the individual (or information about a request for or the receipt of genetic services by such individual or family member of such individual); or

(3) to 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 (or information about a request for the receipt of genetic services by such individual or a family member of such 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 bona fide 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 in-
formation 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 spe-
cific individuals;

(3) where an employment agency requests or re-
quires 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 avail-
able (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 writ-
ten notice of the genetic monitoring to the indi-
vidual;
(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) or (2) of subsection (a) or treated or disclosed in a manner that violates section 206.

SEC. 204. LABOR ORGANIZATION PRACTICES.

(a) USE OF 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 (or information about a request for or the receipt of genetic services by such member or family member of such 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 ge-
nomic information with respect to the member (or in-
formation about a request for or the receipt of ge-
netic services by such member or family member of
such 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 orga-
nization to request, require, or purchase genetic informa-
tion with respect to a member or a family member of the
member (or information about a request for the receipt
of genetic services by such member or a family member
of such member) except—

(1) where a labor organization inadvertently re-
quests 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 serv-
ices offered as part of a bona fide wellness pro-
gram;

(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 imple-
menting 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) or (2) of subsection (a) or treated or disclosed in a manner that violates section 206.

SEC. 205. TRAINING PROGRAMS.

(a) USE OF 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 (or information about a request for or the re-
receipt of genetic services by such individual or a family member of such 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 information about a request for or receipt of genetic services by such individual or family member of such 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 (or information about a re-
quest for the receipt of genetic services by such individual or a family member of such 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 bona fide 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;

(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 spe-
cific individuals;

(3) where the employer, labor organization, or
joint labor-management committee requests or re-
quires 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 docu-
ments 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 employer, labor organization, or
joint labor-management committee 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 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 re-
sults of the monitoring only in aggregate terms
that do not disclose the identity of specific indi-
viduals;

(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) or (2) of subsection (a)
or treated or disclosed in a manner that violates section
206.

**Sec. 206. Confidentiality of Genetic Information.**

(a) **Treatment of information as part of confidential medical record.**—If an employer, employ-
ment agency, labor organization, or joint labor-manage-
ment committee possesses genetic information about an
employee or member (or information about a request for
or receipt of genetic services by such employee or member
or family member of such employee or member), such in-
formation shall be maintained on separate forms and in
separate medical files and be treated as a confidential
medical record of the employee or member.

(b) **Limitation on disclosure.**—An employer, em-
ployment agency, labor organization, or joint labor-man-
agement committee shall not disclose genetic information
concerning an employee or member (or information about
a request for or receipt of genetic services by such em-
ployee or member or family member of such employee or
member) except—

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

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

(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 infor-
mation 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, em-
ployment agency, labor organization, or joint
labor-management committee shall provide the
employee or member with adequate notice to
challenge the court order;
(4) to government officials who are invest-
tigating compliance with this title if the information
is relevant to the investigation; or
(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.

SEC. 207. REMEDIES AND ENFORCEMENT.
(a) EMPLOYEES COVERED BY TITLE VII OF THE
Civil Rights Act of 1964.—
(1) IN GENERAL.—The powers, remedies, and
procedures 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 At-
torney General, or any person, alleging a violation of
title VII of that Act (42 U.S.C. 2000e et seq.) shall
be the powers, remedies, and procedures this title
provides to the Commission, the Attorney General,
or any person, respectively, alleging an unlawful em-
ployment 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 (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 pro-
cedures provided in section 1977A of the Revised
Statutes (42 U.S.C. 1981a), including the limita-
tions 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).

(b) Employees Covered by Government Em-
ployee 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 (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 (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).

(e) 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 (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 (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).

(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 (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 (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).

(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 employ-
ment practice in violation of this title against an em-
ployee 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 (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 pro-
dcedures provided in section 1977A of the Revised
Statutes (42 U.S.C. 1981a), including the limita-
tions 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).

(f) DEFINITION.—In this section, the term “Commis-
sion” means the Equal Employment Opportunity Commissi-
SEC. 208. DISPARATE IMPACT.

(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–d(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 Non-discrimination 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.

(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 Representa-
tives;

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

and

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

(2) COMPENSATION AND EXPENSES.—The
members of the Commission shall not receive com-
pensation for the performance of services for the
Commission, but shall be allowed travel expenses, in-
cluding per diem in lieu of subsistence, at rates au-
thorized 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.

SEC. 209. CONSTRUCTION.

Nothing in this title shall be construed to—

(1) limit the rights or 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) establish a violation under this title for an
employer, employment agency, labor organization, or
joint labor-management committee of a provision of
the amendments made by title I;

(3) limit the rights or protections of an indi-
vidual 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;

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

(5) limit or expand the protections, rights, or
obligations of employees or employers under applica-
ble workers’ compensation laws;

(6) limit the authority of a Federal department
or agency to conduct or sponsor occupational or
other health research that is conducted in compli-
ance with the regulations contained in part 46 of
title 45, Code of Federal Regulations (or any cor-
responding or similar regulation or rule); and

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

SEC. 211. REGULATIONS.

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

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).

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 PROVISION

SEC. 301. SEVERABILITY.

If any provision of this Act, an amendment made by this Act, or the application of such provision or amend-
ment to any person or circumstance is held to be unconsti-
tutional, 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.

Passed the Senate October 14, 2003.

Attest:

Secretary.
AN ACT

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