

106TH CONGRESS
1ST SESSION

H. R. 2555

To establish limitations with respect to the disclosure and use of genetic information in connection with group health plans and health insurance coverage, to provide for consistent standards applicable in connection with hospital care and medical services provided under title 38 of the United States Code, to prohibit employment discrimination on the basis of genetic information and genetic testing, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JULY 19, 1999

Mr. STEARNS (for himself, Mr. BURTON of Indiana, Mr. CANADY of Florida, Mr. COOK, Mr. DEFazio, Mr. DUNCAN, Mr. Faleomavaega, Mr. FARR of California, Mr. FOLEY, Mr. LOBIONDO, Mrs. MEEK of Florida, Mr. MCCOLLUM, Mr. OXLEY, Mrs. ROUKEMA, Mr. SENSENBRENNER, Mr. TAYLOR of North Carolina, and Mr. UPTON) introduced the following bill; which was referred to the Committee on Commerce, and in addition to the Committees on Education and the Workforce, Veterans' Affairs, and Government Reform, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To establish limitations with respect to the disclosure and use of genetic information in connection with group health plans and health insurance coverage, to provide for consistent standards applicable in connection with hospital care and medical services provided under title 38 of the United States Code, to prohibit employment discrimination on the basis of genetic information and genetic testing, and for other purposes.

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

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Genetic Privacy and
5 Nondiscrimination Act of 1999”.

6 **SEC. 2. PROHIBITION OF HEALTH INSURANCE DISCRIMINA-**
7 **TION ON THE BASIS OF GENETIC INFORMA-**
8 **TION.**

9 (a) GROUP COVERAGE.—

10 (1) AMENDMENTS TO PUBLIC HEALTH SERVICE
11 ACT.—

12 (A) INCLUSION OF GENETIC TESTING IN
13 NONDISCRIMINATION REQUIREMENTS.—Section
14 2702(a)(1)(F) of the Public Health Service Act
15 (42 U.S.C. 300gg–1(a)(1)(F)), as added by sec-
16 tion 102(a) of Health Insurance Portability and
17 Accountability Act of 1996, is amended by in-
18 serting “(or a request for, or receipt of, genetic
19 information or a genetic test)” after “genetic
20 information”.

21 (B) PROHIBITIONS AGAINST USE AND DIS-
22 CLOSURE OF GENETIC INFORMATION.—Subpart
23 2 of part A of title XXVII of the Public Health
24 Service Act is amended by adding at the end
25 the following new section:

1 **“SEC. 2707. PROHIBITIONS AGAINST USE AND DISCLOSURE**
2 **OF GENETIC INFORMATION.**

3 “(a) PROHIBITION OF USE OF GENETIC INFORMA-
4 TION.—A group health plan, and a health insurance issuer
5 offering health insurance coverage in connection with a
6 group health plan, may not use genetic information to re-
7 ject, deny, limit, cancel, refuse to renew, establish differen-
8 tial rates or premium payments for, or otherwise affect
9 benefits provided under the plan or health insurance cov-
10 erage offered in connection with the plan.

11 “(b) PROHIBITION OF DISCLOSURE OF GENETIC IN-
12 FORMATION.—

13 “(1) IN GENERAL.—Except as provided in para-
14 graph (2), regardless of the manner in which genetic
15 information was received, or of the source of such
16 information, including information received from an
17 individual, a health insurance issuer in connection
18 with health insurance coverage offered in connection
19 with a group health plan and a group health plan
20 may not disclose or be compelled (by subpoena or
21 any other means) to disclose genetic information
22 about an individual unless such disclosure is specifi-
23 cally authorized by the individual involved or the
24 legal representative of the individual through a writ-
25 ten authorization which includes a description of the
26 information being disclosed, the name of the indi-

1 vidual or entity to whom the disclosure is being
2 made, and the purpose of the disclosure.

3 “(2) EXCEPTIONS.—Notwithstanding para-
4 graph (1), genetic information concerning an indi-
5 vidual may be disclosed if such disclosure—

6 “(A) is authorized under Federal or State
7 criminal laws relating to the identification of in-
8 dividuals, or as is necessary for the purpose of
9 a criminal or death investigation, a criminal or
10 juvenile proceeding, an inquest, or a child fatal-
11 ity review by a multidisciplinary child abuse
12 team;

13 “(B) is required under the specific order of
14 a Federal or State court;

15 “(C) is authorized under Federal or State
16 law for the purpose of establishing paternity; or

17 “(D) is for the purpose of identifying bod-
18 ies.

19 “(3) APPLICATION OF SUBSECTION.—The pro-
20 hibitions of this subsection shall apply to any re-
21 disclosure by any entity after another entity has dis-
22 closed the genetic information.”.

23 “(C) DEFINITIONS.—Section 2791(d) of the
24 Public Health Service Act (42 U.S.C. 300gg—

1 91(d)) is amended by adding at the end the fol-
2 lowing new paragraph:

3 “(15) GENETIC INFORMATION; GENETIC
4 TEST.—

5 “(A) GENETIC INFORMATION.—The term
6 ‘genetic information’ with respect to an indi-
7 vidual means information about the genes of
8 the individual or a member of the individual’s
9 family or about any gene products or inherited
10 characteristics that may derive from the indi-
11 vidual or a member of the individual’s family.

12 “(B) GENETIC TEST.—The term ‘genetic
13 test’ means a test for determining the presence
14 or absence of genetic characteristics in an indi-
15 vidual, including tests of nucleic acids such as
16 DNA, RNA, and mitochondrial DNA, chro-
17 mosomes, or proteins in order to diagnose a ge-
18 netic characteristic.”.

19 (D) CONFORMING AMENDMENT.—Section
20 2723(c) of such Act (42 U.S.C. 300gg–23(c)) is
21 amended by striking “section 2704” and insert-
22 ing “sections 2704 and 2707”.

23 (2) ERISA AMENDMENTS.—

24 (A) INCLUSION OF GENETIC TESTING IN
25 NONDISCRIMINATION REQUIREMENTS.—Section

1 702(a)(1)(F) of the Employee Retirement In-
2 come Security Act of 1974 (29 U.S.C.
3 1182(a)(1)(F)) is amended by inserting “(or a
4 request for, or receipt of, genetic information
5 or a genetic test)” after “genetic information”.

6 (B) PROHIBITION AGAINST USE AND DIS-
7 CLOSURE OF GENETIC INFORMATION.—Subpart
8 B of part 7 of subtitle B of title I of the Em-
9 ployee Retirement Income Security Act of 1974
10 is amended by adding at the end the following
11 new section:

12 **“SEC. 714. PROHIBITION AGAINST USE AND DISCLOSURE**
13 **OF GENETIC INFORMATION.**

14 “(a) PROHIBITION OF USE OF GENETIC INFORMA-
15 TION.—A group health plan, and a health insurance in-
16 surer offering health insurance coverage in connection
17 with a group health plan, may not use genetic information
18 to reject, deny, limit, cancel, refuse to renew, increase the
19 rates of, or otherwise affect benefits provided under the
20 plan or health insurance coverage offered in connection
21 with the plan.

22 “(b) PROHIBITION OF DISCLOSURE OF GENETIC IN-
23 FORMATION.—

24 “(1) IN GENERAL.—Except as provided in para-
25 graph (2), regardless of the manner in which genetic

1 information was received, or of the source of such
2 information, including information received from an
3 individual, a health insurance issuer in connection
4 with health insurance coverage offered in connection
5 with a group health plan and a group health plan
6 may not disclose or be compelled (by subpoena or
7 any other means) to disclose genetic information
8 about an individual unless such disclosure is specifi-
9 cally authorized by the individual involved or the
10 legal representative of the individual through a writ-
11 ten authorization which includes a description of the
12 information being disclosed, the name of the indi-
13 vidual or entity to whom the disclosure is being
14 made, and the purpose of the disclosure.

15 “(2) EXCEPTIONS.—Notwithstanding para-
16 graph (1), genetic information concerning an indi-
17 vidual may be disclosed if such disclosure—

18 “(A) is authorized under Federal or State
19 criminal laws relating to the identification of in-
20 dividuals, or as is necessary for the purpose of
21 a criminal or death investigation, a criminal or
22 juvenile proceeding, an inquest, or a child fatal-
23 ity review by a multidisciplinary child abuse
24 team;

1 “(B) is required under the specific order of
2 a Federal or State court;

3 “(C) is authorized under Federal or State
4 law for the purpose of establishing paternity; or

5 “(D) is for the purpose of identifying bod-
6 ies.

7 “(3) APPLICATION OF SUBSECTION.—The pro-
8 hibitions of this subsection shall apply to any re-
9 disclosure by any entity after another entity has dis-
10 closed the genetic information.”.

11 (C) DEFINITIONS.—Section 733(d) of the
12 Employee Retirement Income Security Act of
13 1974 (29 U.S.C. 1186(d)) is amended by add-
14 ing at the end the following new paragraph:

15 “(5) GENETIC INFORMATION; GENETIC TEST.—

16 “(A) The term ‘genetic information’ with
17 respect to an individual means information
18 about the genes of the individual or a member
19 of the individual’s family or about any gene
20 products or inherited characteristics that may
21 derive from the individual or a member of the
22 individual’s family.

23 “(B) The term ‘genetic test’ means a test
24 for determining the presence or absence of ge-
25 netic characteristics in an individual, including

1 tests of nucleic acids such as DNA, RNA, and
2 mitochondrial DNA, chromosomes, or proteins
3 in order to diagnose a genetic characteristic.”.

4 (D) CONFORMING AMENDMENTS.—(i) Sec-
5 tion 731(c) of such Act (29 U.S.C. 1191(c)) is
6 amended by striking “section 711” and insert-
7 ing “sections 711 and 714”.

8 (ii) Section 732(a) of such Act (29 U.S.C.
9 1191a(a)) is amended by striking “section 711”
10 and inserting “sections 711 and 714”.

11 (iii) The table of contents in section 1 of
12 such Act is amended by inserting after the item
13 relating to section 712 the following new item:

“Sec. 714. Prohibition against use and disclosure of genetic information.”.

14 (b) INDIVIDUAL HEALTH INSURANCE.—Part B of
15 title XXVII of the Public Health Service Act is amended
16 by inserting after section 2752 the following new section:

17 **“SEC. 2753. PROHIBITION AGAINST USE AND DISCLOSURE**
18 **OF GENETIC INFORMATION.**

19 “The provisions of section 2707 shall apply to health
20 insurance coverage offered by a health insurance issuer
21 in the individual market in the same manner as it applies
22 to health insurance coverage offered by a health insurance
23 issuer in connection with a group health plan in the small
24 or large group market.”.

1 (c) TREATMENT OF GENETIC INFORMATION UNDER
2 PROGRAMS ADMINISTERED BY THE DEPARTMENT OF
3 VETERANS' AFFAIRS.—

4 (1) IN GENERAL.—Subchapter III of chapter
5 73 of title 38, United States Code, is amended by
6 inserting after section 7334 the following new sec-
7 tion:

8 **“§ 7335. Treatment of genetic information**

9 “The Secretary shall prescribe standards, relating to
10 the use and disclosure of genetic information in connection
11 with hospital care and medical services provided under
12 chapter 17 of this title, which are consistent with the
13 standards applicable under section 2707 of the Public
14 Health Service Act (relating to prohibitions against use
15 and disclosure of genetic information) in connection with
16 benefits provided by group health plans and health insur-
17 ance coverage offered by health insurance issuers.”.

18 (2) CONFORMING AMENDMENT.—The table of
19 sections for chapter 73 of title 38, United States
20 Code is amended by inserting after the item relating
21 to section 7334 the following new item:

“7335. Treatment of genetic information.”.

22 (d) EFFECTIVE DATES.—(1) The amendments made
23 by subsection (a) shall apply with respect to group health
24 plans for plan years beginning on or after January 1,
25 2000.

1 (2) The amendments made by subsection (b) shall
2 apply with respect to health insurance coverage offered,
3 sold, issued, renewed, in effect, or operated in the indi-
4 vidual market on or after such date.

5 (3) The amendments made by subsection (c) shall
6 apply with respect to hospital care and medical services
7 provided on or after such date.

8 **SEC. 3. PROHIBITION OF EMPLOYMENT PRACTICES IN-**
9 **VOLVING GENETIC INFORMATION.**

10 (a) ACQUISITION AND USE OF GENETIC INFORMA-
11 TION AND GENETIC TESTING.—

12 (1) IN GENERAL.—Subject to paragraph (2), it
13 shall be an unlawful employment practice for an
14 employer—

15 (A) to attempt to acquire, to acquire, or to
16 use the genetic information of an employee or
17 applicant for employment, or

18 (B) to require a genetic test of an em-
19 ployee or applicant for employment,
20 for the purpose of distinguishing among employees
21 or applicants for employment or for the purpose of
22 discriminating against or restricting any right or
23 benefit otherwise due or available to an employee or
24 applicant for employment, in connection with any
25 matter relating to employment or employment op-

1 portunities, including terms and conditions of em-
2 ployment, privileges and benefits for employees, and
3 termination of employment.

4 (2) EXCEPTION.—Paragraph (1) shall not
5 apply with respect to any act described in paragraph
6 (1) with respect to genetic information or any re-
7 quirement described in paragraph (1) for a genetic
8 test if such act or requirement—

9 (A) is job-related and consistent with busi-
10 ness necessity, or

11 (B) is required under Federal or State law.

12 (b) NONDISCLOSURE AND CONFIDENTIALITY OF GE-
13 NETIC INFORMATION.—It shall be an unlawful employ-
14 ment practice for an employer—

15 (1) to allow access to genetic information of
16 employees to any person other than persons whose
17 duties or responsibilities in connection with the em-
18 ployer require access to such information for pur-
19 poses consistent with subsection (a), or

20 (2) to establish or maintain access by the em-
21 ployer to an employee's genetic information which
22 has been acquired—

23 (A) by any employee welfare benefit plan
24 established or maintained by the employer in

1 which such employee is a participant (or by any
2 other fiduciary of such a plan), or

3 (B) by any health insurance issuer offering
4 health insurance coverage in connection with a
5 group health plan in which such employee is a
6 participant,

7 without the prior, written, and informed consent of the
8 employee, signed by the employee, setting forth the person
9 or persons to whom access to such information is to be
10 allowed.

11 (c) ENFORCEMENT.—The powers, remedies, and pro-
12 cedures set forth in sections 705 through 709 of the Civil
13 Rights Act of 1964 shall be the powers, remedies, and pro-
14 cedures this section provides to any person alleging a vio-
15 lation of this section.

16 (d) DEFINITIONS.—As used in this section:

17 (1) EMPLOYER; EMPLOYEE.—The terms “em-
18 ployer” and “employee” have the meanings given
19 such terms, respectively, in section 701 of the Civil
20 Rights Act of 1964 (42 U.S.C. 2000e).

21 (2) EMPLOYMENT OR EMPLOYMENT OPPORTU-
22 NITIES.—The term “employment or employment op-
23 portunities” includes job application procedures, hir-
24 ing, advancement, discharge, compensation, job

1 training, or any other term, condition, or privilege of
2 employment.

3 (3) GENETIC INFORMATION.—The term “ge-
4 netic information” with respect to an individual
5 means information about the genes of the individual
6 or a member of the individual’s family or about any
7 gene products or inherited characteristics that may
8 derive from the individual or a member of the indi-
9 vidual’s family.

10 (4) GENETIC TEST.—The term “genetic test”
11 means a test for determining the presence or ab-
12 sence of genetic characteristics in an individual, in-
13 cluding tests of nucleic acids such as DNA, RNA,
14 and mitochondrial DNA, chromosomes, or proteins
15 in order to diagnose a genetic characteristic.

16 (5) OTHER TERMS.—

17 (A) GROUP HEALTH PLAN; HEALTH IN-
18 SURANCE ISSUER; HEALTH INSURANCE COV-
19 ERAGE.—The terms “group health plan”,
20 “health insurance issuer”, and “health insur-
21 ance coverage” have the meanings given such
22 terms, respectively, in section 733 of the Em-
23 ployee Retirement Income Security Act of 1974
24 (29 U.S.C. 1191b(a)).

1 (B) EMPLOYEE WELFARE BENEFIT PLAN;
2 PARTICIPANT.—The terms “employee welfare
3 benefit plan” and “participant” have the mean-
4 ings given such terms, respectively, in section 3
5 of the Employee Retirement Income Security
6 Act of 1974 (29 U.S.C. 1002).

7 **SEC. 4. FURTHER RECOMMENDATION BY THE NATIONAL**
8 **BIOETHICS ADVISORY COMMISSION.**

9 Not later than 1 year after the date of the enactment
10 of this Act, the National Bioethics Advisory Commission
11 shall prepare and submit to the appropriate committees
12 of Congress a report containing recommendations on—

13 (1) the development and implementation of
14 standards to provide increased protection for the col-
15 lection, storage, and use of identifiable DNA sam-
16 ples and genetic information obtained from those
17 samples; and

18 (2) the development and implementation of ap-
19 propriate standards for the acquisition and retention
20 of genetic information in all settings, including ap-
21 propriate exceptions.

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