

105TH CONGRESS
1ST SESSION

H. R. 2198

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 17, 1997

Mr. STEARNS (for himself, Mr. ARMEY, Mr. BISHOP, Mr. BROWN of Ohio, Mr. CANADY of Florida, Mr. DAVIS of Virginia, Mr. DEFazio, Mr. DUNCAN, Mr. Faleomavaega, Mr. FARR of California, Mr. FOLEY, Mrs. FOWLER, Mr. GEKAS, Mr. GILLMOR, Mr. GILMAN, Mr. GONZALEZ, Mr. GREEN, Mr. HERGER, Mr. HYDE, Mrs. JOHNSON of Connecticut, Mr. KENNEDY of Massachusetts, Ms. LOFGREN, Mr. MCCOLLUM, Mr. MCHUGH, Ms. MCKINNEY, Mr. NADLER, Mr. OBERSTAR, Mr. OXLEY, Mr. SENSENBRENNER, Mr. SHADEGG, Mr. SMITH of New Jersey, Mr. STUMP, Mr. TAYLOR of North Carolina, Mr. TRAFICANT, Mr. UPTON, Mr. WAXMAN, Mr. WELDON of Florida, and Ms. WOOLSEY) introduced the following bill; which was referred to the Committee on Commerce, and in addition to the Committees on Government Reform and Oversight, Education and the Workforce, and Veterans' Affairs, 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 1997”.

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

1 Service Act, as amended by section 703(a) of
2 Public Law 104–204, is amended by adding at
3 the end the following new section:

4 **“SEC. 2706. PROHIBITIONS AGAINST USE AND DISCLOSURE**
5 **OF GENETIC INFORMATION.**

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

14 “(b) PROHIBITION OF DISCLOSURE OF GENETIC IN-
15 FORMATION.—

16 “(1) IN GENERAL.—Except as provided in para-
17 graph (2), regardless of the manner in which genetic
18 information was received, or of the source of such
19 information, including information received from an
20 individual, a health insurance issuer in connection
21 with health insurance coverage offered in connection
22 with a group health plan and a group health plan
23 may not disclose or be compelled (by subpoena or
24 any other means) to disclose genetic information
25 about an individual unless such disclosure is specifi-

1 cally authorized by the individual involved or the
2 legal representative of the individual through a writ-
3 ten authorization which includes a description of the
4 information being disclosed, the name of the individ-
5 ual or entity to whom the disclosure is being made,
6 and the purpose of the disclosure.

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

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

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

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

21 “(D) is for the purpose of identifying bod-
22 ies.

23 “(3) APPLICATION OF SUBSECTION.—The pro-
24 hibitions of this subsection shall apply to any re-

disclosure by any entity after another entity has disclosed the genetic information.”.

(C) 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 new paragraph:

“(15) GENETIC INFORMATION; GENETIC TEST.—

“(A) GENETIC INFORMATION.—The term ‘genetic information’ with respect to an individual means information about the genes of the individual or a member of the individual’s family or about any gene products or inherited characteristics that may derive from the individual or a member of the individual’s family.

“(B) GENETIC TEST.—The term ‘genetic test’ means a test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA, and mitochondrial DNA, chromosomes, or proteins in order to diagnose a genetic characteristic.”.

(D) CONFORMING AMENDMENT.—Section 2723(c) of such Act (42 U.S.C. 300gg–23(c)), as amended by section 604(b)(2) of Public Law 104–

1 204, is amended by striking “section 2704” and in-
 2 serting “sections 2704 and 2706”.

3 (2) ERISA AMENDMENTS.—

4 (A) INCLUSION OF GENETIC TESTING IN
 5 NONDISCRIMINATION REQUIREMENTS.—Section
 6 702(a)(1)(F) of the Employee Retirement In-
 7 come Security Act of 1974 (29 U.S.C.
 8 1182(a)(1)(F)), as added by section 101(a) of
 9 Health Insurance Portability and Accountability
 10 Act of 1996, is amended by inserting “(or a re-
 11 quest for, or receipt of, genetic information or
 12 a genetic test)” after “genetic information”.

13 (B) PROHIBITION AGAINST USE AND DIS-
 14 CLOSURE OF GENETIC INFORMATION.—Subpart
 15 B of part 7 of subtitle B of title I of the Em-
 16 ployee Retirement Income Security Act of 1974,
 17 as amended by section 702(a) of Public Law
 18 104–204, is amended by adding at the end the
 19 following new section:

20 **“SEC. 713. PROHIBITION AGAINST USE AND DISCLOSURE**
 21 **OF GENETIC INFORMATION.**

22 “(a) PROHIBITION OF USE OF GENETIC INFORMA-
 23 TION.—A group health plan, and a health insurance in-
 24 surer offering health insurance coverage in connection
 25 with a group health plan, may not use genetic information

1 to reject, deny, limit, cancel, refuse to renew, increase the
2 rates of, or otherwise affect benefits provided under the
3 plan or health insurance coverage offered in connection
4 with the plan.

5 “(b) PROHIBITION OF DISCLOSURE OF GENETIC IN-
6 FORMATION.—

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

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

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

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

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

12 “(D) is for the purpose of identifying bod-
13 ies.

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

18 (C) DEFINITIONS.—Section 733(d) of the
19 Employee Retirement Income Security Act of
20 1974 (29 U.S.C. 1186(d)) is amended by add-
21 ing at the end the following new paragraph:

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

23 “(A) The term ‘genetic information’ with
24 respect to an individual means information
25 about the genes of the individual or a member

1 of the individual's family or about any gene
2 products or inherited characteristics that may
3 derive from the individual or a member of the
4 individual's family.

5 “(B) The term ‘genetic test’ means a test
6 for determining the presence or absence of ge-
7 netic characteristics in an individual, including
8 tests of nucleic acids such as DNA, RNA, and
9 mitochondrial DNA, chromosomes, or proteins
10 in order to diagnose a genetic characteristic.”.

11 (D) CONFORMING AMENDMENTS.—(i) Sec-
12 tion 731(c) of such Act (29 U.S.C. 1191(c)), as
13 amended by section 603(b)(1) of Public Law
14 104–204, is amended by striking “section 711”
15 and inserting “sections 711 and 713”.

16 (ii) Section 732(a) of such Act (29 U.S.C.
17 1191a(a)), as amended by section 603(b)(2) of Pub-
18 lic Law 104–204, is amended by striking “section
19 711” and inserting “sections 711 and 713”.

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

“Sec. 713. Prohibition against use and disclosure of genetic information.”.

23 (b) INDIVIDUAL HEALTH INSURANCE.—Part B of
24 title XXVII of the Public Health Service Act, as amended

1 by section 605(a) of Public Law 104–204, is amended by
2 inserting after section 2751 the following new section:

3 **“SEC. 2752. PROHIBITION AGAINST USE AND DISCLOSURE**
4 **OF GENETIC INFORMATION.**

5 “The provisions of section 2706 shall apply to health
6 insurance coverage offered by a health insurance issuer
7 in the individual market in the same manner as it applies
8 to health insurance coverage offered by a health insurance
9 issuer in connection with a group health plan in the small
10 or large group market.”.

11 (c) TREATMENT OF GENETIC INFORMATION UNDER
12 PROGRAMS ADMINISTERED BY THE DEPARTMENT OF
13 VETERANS’ AFFAIRS.—

14 (1) IN GENERAL.—Subchapter III of chapter
15 73 of title 38, United States Code, is amended by
16 inserting after section 7334 the following new sec-
17 tion:

18 **“§ 7335. Treatment of genetic information**

19 “The Secretary shall prescribe standards, relating to
20 the use and disclosure of genetic information in connection
21 with hospital care and medical services provided under
22 chapter 17 of this title, which are consistent with the
23 standards applicable under section 2706 of the Public
24 Health Service Act (relating to prohibitions against use
25 and disclosure of genetic information) in connection with

1 benefits provided by group health plans and health insur-
 2 ance coverage offered by health insurance issuers.”.

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

“7335. Treatment of genetic information.”.

7 (d) EFFECTIVE DATES.—(1) The amendments made
 8 by subsection (a) shall apply with respect to group health
 9 plans for plan years beginning on or after January 1,
 10 1998.

11 (2) The amendments made by subsection (b) shall
 12 apply with respect to health insurance coverage offered,
 13 sold, issued, renewed, in effect, or operated in the individ-
 14 ual market on or after such date.

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

18 **SEC. 3. PROHIBITION OF EMPLOYMENT PRACTICES IN-**
 19 **VOLVING GENETIC INFORMATION.**

20 (a) ACQUISITION AND USE OF GENETIC INFORMA-
 21 TION AND GENETIC TESTING.—

22 (1) IN GENERAL.—Subject to paragraph (2), it
 23 shall be an unlawful employment practice for an em-
 24 ployer—

1 (A) to attempt to acquire, to acquire, or to
2 use the genetic information of an employee or
3 applicant for employment, or

4 (B) to require a genetic test of an em-
5 ployee or applicant for employment,
6 for the purpose of distinguishing among employees
7 or applicants for employment or for the purpose of
8 discriminating against or restricting any right or
9 benefit otherwise due or available to an employee or
10 applicant for employment, in connection with any
11 matter relating to employment or employment op-
12 portunities, including terms and conditions of em-
13 ployment, privileges and benefits for employees, and
14 termination of employment.

15 (2) EXCEPTION.—Paragraph (1) shall not
16 apply with respect to any act described in paragraph
17 (1) with respect to genetic information or any re-
18 quirement described in paragraph (1) for a genetic
19 test if such act or requirement—

20 (A) is job-related and consistent with busi-
21 ness necessity, or

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

23 (b) NONDISCLOSURE AND CONFIDENTIALITY OF GE-
24 NETIC INFORMATION.—It shall be an unlawful employ-
25 ment practice for an employer—

1 (1) to allow access to genetic information of
2 employees to any person other than persons whose
3 duties or responsibilities in connection with the em-
4 ployer require access to such information for pur-
5 poses consistent with subsection (a), or

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

9 (A) by any employee welfare benefit plan
10 established or maintained by the employer in
11 which such employee is a participant (or by any
12 other fiduciary of such a plan), or

13 (B) by any health insurance issuer offering
14 health insurance coverage in connection with a
15 group health plan in which such employee is a
16 participant,

17 without the prior, written, and informed consent of the
18 employee, signed by the employee, setting forth the person
19 or persons to whom access to such information is to be
20 allowed.

21 (c) ENFORCEMENT.—The powers, remedies, and pro-
22 cedures set forth in sections 705 through 709 of the Civil
23 Rights Act of 1964 shall be the powers, remedies, and pro-
24 cedures this section provides to any person alleging a vio-
25 lation of this section.

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

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

6 (2) EMPLOYMENT OR EMPLOYMENT OPPORTU-
7 NITIES.—The term “employment or employment op-
8 portunities” includes job application procedures, hir-
9 ing, advancement, discharge, compensation, job
10 training, or any other term, condition, or privilege of
11 employment.

12 (3) GENETIC INFORMATION.—The term “ge-
13 netic information” with respect to an individual
14 means information about the genes of the individual
15 or a member of the individual’s family or about any
16 gene products or inherited characteristics that may
17 derive from the individual or a member of the indi-
18 vidual’s family.

19 (4) GENETIC TEST.—The term “genetic test”
20 means a test for determining the presence or ab-
21 sence of genetic characteristics in an individual, in-
22 cluding tests of nucleic acids such as DNA, RNA,
23 and mitochondrial DNA, chromosomes, or proteins
24 in order to diagnose a genetic characteristic.

25 (5) OTHER TERMS.—

(A) GROUP HEALTH PLAN; HEALTH INSURANCE ISSUER; HEALTH INSURANCE COVERAGE.—The terms “group health plan”, “health insurance issuer”, and “health insurance coverage” have the meanings given such terms, respectively, in section 733 of the Employee Retirement Income Security Act of 1974 (29 U.S.C. 1191b(a)).

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

SEC. 4. FURTHER RECOMMENDATION BY THE NATIONAL BIOETHICS ADVISORY COMMISSION.

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

- (1) the development and implementation of standards to provide increased protection for the collection, storage, and use of identifiable DNA samples and genetic information obtained from those samples; and

- 1 (2) the development and implementation of ap-
- 2 appropriate standards for the acquisition and retention
- 3 of genetic information in all settings, including ap-
- 4 propriate exceptions.

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