

108TH CONGRESS
1ST SESSION

H. R. 3636

To amend the Public Health Service Act to prohibit health discrimination against individuals and their family members on the basis of genetic information, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 21, 2003

Mr. STEARNS introduced the following bill; which was referred to the
Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to prohibit health discrimination against individuals and their family members on the basis of genetic information, 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 2003”.

1 **SEC. 2. AMENDMENTS TO THE PUBLIC HEALTH SERVICE**
2 **ACT.**

3 (a) AMENDMENTS RELATING TO THE GROUP MAR-
4 KET.—

5 (1) PROHIBITION OF HEALTH DISCRIMINATION
6 ON THE BASIS OF GENETIC INFORMATION IN THE
7 GROUP MARKET.—

8 (A) NO ENROLLMENT RESTRICTION FOR
9 GENETIC SERVICES.—Section 2702(a)(1)(F) of
10 the Public Health Service Act (42 U.S.C.
11 300gg–1(a)(1)(F)) is amended by inserting be-
12 fore the period the following: “(including infor-
13 mation about a request for or receipt of genetic
14 services)”.
15

16 (B) NO DISCRIMINATION IN PREMIUMS
17 BASED ON PREDICTIVE GENETIC INFORMA-
18 TION.—Subpart 2 of part A of title XXVII of
19 the Public Health Service Act (42 U.S.C.
20 300gg–4 et seq.) is amended by adding at the
end the following new section:

21 **“SEC. 2707. PROHIBITING PREMIUM DISCRIMINATION**
22 **AGAINST GROUPS ON THE BASIS OF PRE-**
23 **DICTIVE GENETIC INFORMATION IN THE**
24 **GROUP MARKET.**

25 “A group health plan, or a health insurance issuer
26 offering group health insurance coverage in connection

1 with a group health plan shall not adjust premium or con-
 2 tribution amounts for a group on the basis of predictive
 3 genetic information concerning any individual (including
 4 a dependent) or family member of the individual (includ-
 5 ing information about a request for or receipt of genetic
 6 services).”.

7 (C) CONFORMING AMENDMENT.—Section
 8 2702(b) of the Public Health Service Act (42
 9 U.S.C. 300gg–1(b)) is amended by adding at
 10 the end the following:

11 “(3) REFERENCE TO RELATED PROVISION.—
 12 For a provision prohibiting the adjustment of pre-
 13 mium or contribution amounts for a group under a
 14 group health plan on the basis of predictive genetic
 15 information (including information about a request
 16 for or receipt of genetic services), see section 2707.”.

17 (2) DEFINITIONS.—Section 2791(d) of the Pub-
 18 lic Health Service Act (42 U.S.C. 300gg–91(d)) is
 19 amended by adding at the end the following:

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

22 “(A) the spouse of the individual;

23 “(B) a dependent child of the individual;

24 and

1 “(C) all other individuals related by blood
2 to the individual or the spouse or child de-
3 scribed in subparagraph (A) or (B).

4 “(16) GENETIC SERVICES.—The term ‘genetic
5 services’ means health services for an individual pro-
6 vided to interpret and assess predictive genetic infor-
7 mation for diagnostic or therapeutic purposes as well
8 as to counsel individuals regarding the use of spe-
9 cific predictive genetic information.

10 “(17) PREDICTIVE GENETIC INFORMATION.—

11 “(A) IN GENERAL.—The term ‘predictive
12 genetic information’ means individually identifi-
13 able information which identifies the presence,
14 absence, variation, alteration, or modification of
15 a human gene or genes that—

16 “(i) are scientifically or medically
17 identifiable; and

18 “(ii) are—

19 “(I) known to be a primary cause
20 of a disease, disorder, or syndrome in
21 a person, or associated with a signifi-
22 cantly increased statistical risk of de-
23 velopment of a disease, disorder, or
24 syndrome in a person, but which have
25 not resulted in signs in the person

1 that would otherwise permit diagnosis
2 of the disease, disorder, or syndrome;
3 or

4 “(II) associated with an in-
5 creased statistical risk of a person
6 having offspring with a disease, dis-
7 order, or syndrome.

8 “(B) LIMITATIONS.—The term ‘predictive
9 genetic information’ does not include—

10 “(i) information from which individual
11 identifiers are removed, encoded, or
12 encrypted to prevent disclosure of the indi-
13 vidual’s identity;

14 “(ii) information for research con-
15 ducted in compliance with the regulations
16 and protections provided for under parts
17 50 and 56 of title 21 and under part 46
18 of title 45, Code of Federal Regulations; or

19 “(iii) information related to a mani-
20 fested disease, disorder, impairment, or
21 condition which could be reasonably de-
22 tected by a health care professional with
23 appropriate training and expertise in the
24 field of medicine involved.

1 “(18) PREDICTIVE GENETIC TEST.—The term
 2 ‘predictive genetic test’ means a laboratory test on
 3 a biological sample of a person performed solely to
 4 obtain predictive genetic information.”.

5 (b) AMENDMENTS RELATING TO THE INDIVIDUAL
 6 MARKET.—The first subpart 3 of part B of title XXVII
 7 of the Public Health Service Act (42 U.S.C. 300gg–51 et
 8 seq.) (relating to other requirements) is amended by add-
 9 ing at the end the following:

10 **“SEC. 2753. PROHIBITION OF HEALTH DISCRIMINATION ON**
 11 **THE BASIS OF PREDICTIVE GENETIC INFOR-**
 12 **MATION.**

13 “(a) PROHIBITION ON PREDICTIVE GENETIC INFOR-
 14 MATION AS A CONDITION OF ELIGIBILITY.—A health in-
 15 surance issuer offering health insurance coverage in the
 16 individual market may not use predictive genetic informa-
 17 tion as a condition of eligibility of an individual to enroll
 18 in individual health insurance coverage (including infor-
 19 mation about a request for or receipt of genetic services).

20 “(b) PROHIBITION ON PREDICTIVE GENETIC INFOR-
 21 MATION IN SETTING PREMIUM RATES.—A health insur-
 22 ance issuer offering health insurance coverage in the indi-
 23 vidual market shall not adjust premium rates for individ-
 24 uals on the basis of predictive genetic information con-
 25 cerning such an individual (including a dependent) or a

1 family member of the individual (including information
2 about a request for or receipt of genetic services).”.

3 (c) EFFECTIVE DATE.—The amendments made by
4 this section shall apply with respect to—

5 (1) group health plans, and health insurance
6 coverage offered in connection with group health
7 plans, for plan years beginning after 1 year after the
8 date of enactment of this Act; and

9 (2) health insurance coverage offered, sold,
10 issued, renewed, in effect, or operated in the indi-
11 vidual market after 1 year after the date of enact-
12 ment of this Act.

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