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104TH CONGRESS

2D SESSION H. R. 4008 To prohibit health insurers and group health plans from discriminating

against individuals on the basis of genetic information.

IN THE HOUSE OF REPRESENTATIVES AUGUST 2, 1996 Mr. SOLOMON introduced the following bill; which was referred to the Commit-

tee on Commerce, and in addition to the Committee on Economic and Educational Opportunities, for a period to be subsequently determined by
the Speaker, in each case for consideration of such provisions as fall with-
in the jurisdiction of the committee concerned

A BILL

To prohibit health insurers and group health plans from
discriminating against individuals on the basis of genetic
information.

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 Information
5 Health Insurance Nondiscrimination Act of 1996’’.

2

•HR 4008 IH

1 SEC. 2. PROHIBITION OF HEALTH INSURANCE DISCRIMINA-
2 TION ON THE BASIS OF GENETIC INFORMA-
3 TION.

4 (a) IN GENERAL.—

5 (1) APPLICATION TO INSURERS.—An insurer
6 may not deny, cancel, or refuse to renew health in-

7 surance coverage, may not vary the premiums,
8 terms, or conditions for health insurance coverage,

9 and may not otherwise discriminate with respect to
10 an individual with respect to health insurance cov-
11 erage—

12 (A) on the basis of genetic information, or
13 (B) on the basis of the request for, or re-

14 ceipt of, genetic information or a genetic test.
15 (2) APPLICATION TO GROUP HEALTH PLANS.—
16 A group health plan may not establish rules relating

17 to who may be a participant or beneficiary with re-
18 spect to the plan, may not vary the premiums,

19 terms, or conditions for benefits under the plan, and
20 otherwise may not otherwise discriminate with re-
21 spect to a participant or beneficiary under the

22 plan—
23 (A) on the basis of genetic information, or
24 (B) on the basis of the request for, or re-

25 ceipt of, genetic information or a genetic test.

3

•HR 4008 IH

1 (b) LIMITATION ON COLLECTION AND DISCLOSURE
2 OF GENETIC INFORMATION.—
3 (1) LIMITATION ON COLLECTION.—An insurer

4 may not request or require an individual to whom
5 the insurer provides health insurance coverage (or

6 an individual who desires the insurer to provide
7 health insurance coverage), and a group health plan

8 may not request or require a participant or bene-
9 ficiary under the plan (or an individual who desires
10 to become such a participant or beneficiary), to dis-

11 close any genetic information or to obtain any ge-
12 netic test.

13 (2) RESTRICTION ON DISCLOSURE.—Subject to
14 paragraph (3), an insurer or group health plan may

15 not disclose genetic information about an individual
16 (regardless of how the information was obtained)
17 without a prior written authorization of the individ-

18 ual (or legal representative of the individual) that in-

19 cludes—

20 (A) a description of the information being

21 disclosed,
22 (B) the name of the individual or person to

23 whom the disclosure is being made, and
24 (C) the purpose of the disclosure.
25 Such authorization is required for each disclosure.

4

•HR 4008 IH

1 (3) EXCEPTIONS TO DISCLOSURE RESTRIC-
2 TION.—Genetic information concerning an individual

3 may be disclosed by an insurer or group health plan

4 if such disclosure—

5 (A) is authorized under criminal laws re-

6 lating to the identification of individuals, or is
7 authorized under Federal or State law and is

8 necessary for the purpose of a criminal or death
9 investigation, a criminal or juvenile proceeding,

10 an inquest, or a child fatality review by a multi-
11 disciplinary child abuse team;
12 (B) is required under the specific order of

13 a court;
14 (C) is authorized under law for the pur-

15 pose of establishing paternity;
16 (D) is for the purpose of furnishing genetic
17 information relating to a decedent to the blood

18 relatives of the decedent for the purpose of
19 medical diagnosis; or
20 (E) is for the purpose of identifying a

21 body.
22 (c) DISCLOSURE OF RIGHTS.—Each insurer and

23 group health plan shall provide for disclosure of the rights 24 under this section in such manner as the Secretary may

25 require.

5

•HR 4008 IH

1 (d) ENFORCEMENT.—
2 (1) INSURERS.—
3 (A) ENFORCEMENT BY STATE INSURANCE
4 COMMISSIONER.—

5 (i) IN GENERAL.—The requirements

6 established under subsections (a), (b), and
7 (c) insofar as they apply to insurers shall

8 be enforced by the State insurance com-

9 missioner for the State involved or the offi-

10 cial or officials designated by the State.

11 (ii) ENFORCEMENT PLAN.—Each
12 State shall require that an insurer offering

13 or renewing health insurance coverage in
14 such State meet such requirements pursu-

15 ant to an enforcement plan filed by the
16 State with the Secretary.
17 (B) ENFORCEMENT BY SECRETARY.—In
18 the case of the failure of a State to file such a

19 plan or substantially enforce the plan, the Sec-

20 retary shall implement an enforcement plan in
21 such State. Under the Secretary’s enforcement
22 plan, each insurer operating in such State that

23 violates a requirement of subsection (a), (b), or
24 (c) shall be subject to civil enforcement under

25 sections 502, 504, 506, and 510 of the Em-

6

•HR 4008 IH

1 ployee Retirement Income Security Act of 1974.
2 For purposes of applying the previous sentence,

3 any reference in the sections referred to in such
4 sentence to the Secretary of Labor is deemed a
5 reference to the Secretary of Health and

6 Human Services.
7 (2) GROUP HEALTH PLANS.—With respect to

8 group health plans, the Secretary of Labor shall en-
9 force the requirements established under subsections
10 (a), (b), and (c) in the same manner as provided for

11 under sections 502, 504, 506, and 510 of the Em-
12 ployee Retirement Income Security Act of 1974.

13 (2) PRIVATE RIGHT OF ACTION.—A person may
14 bring a civil action—
15 (A) to enjoin any act or practice which vio-

16 lates subsection (a) or (b),
17 (B) to obtain other appropriate equitable

18 relief (i) to redress such violations, or (ii) to en-
19 force any such subsections, or
20 (C) to obtain other legal relief, including

21 monetary damages.
22 (3) JURISDICTION.—State courts of competent

23 jurisdiction and district courts of the United States
24 have concurrent jurisdiction of actions under this

25 subsection. The district courts of the United States

7

•HR 4008 IH

1 shall have jurisdiction, without respect to the
2 amount in controversy or the citizenship of the par-

3 ties, to grant the relief provided for in paragraph (2)
4 in any action.
5 (4) VENUE.—For purposes of this subsection

6 the venue provisions of section 1391 of title 28,
7 United States Code, shall apply.

8 (5) REGULATIONS.—The Secretary and the
9 Secretary of Labor (in consultation with the Sec-

10 retary in relation to the application of this section
11 with respect to group health plans) may promulgate
12 such regulations as may be necessary or appropriate

13 to carry out this section.
14 (e) APPLICABILITY.—
15 (1) PREEMPTION OF STATE LAW.—A State may

16 establish or enforce requirements for insurers or
17 health insurance coverage with respect to the subject

18 matter of this section, but only if such requirements
19 are not less restrictive than the requirements estab-
20 lished under subsections (a), (b), and (c).

21 (2) RULE OF CONSTRUCTION.—Nothing in this
22 section shall be construed to affect or modify the

23 provisions of section 514 of the Employee Retire-
24 ment Income Security Act of 1974.

8

•HR 4008 IH

1 (3) CONTINUATION.—Nothing in this section
2 shall be construed as requiring a group health plan

3 to provide benefits to a particular participant or
4 beneficiary.
5 (f) DEFINITIONS.—For purposes of this Act:

6 (1) GENETIC INFORMATION.—The term ‘‘ge-
7 netic information’’ means the information about

8 genes, gene products, or inherited characteristics
9 that may derive from an individual or a blood-rel-

10 ative of the individual.

11 (2) GENETIC TEST.—The term ‘‘genetic test’’
12 means a test for determining the presence or ab-

13 sence of genetic characteristics in an individual.
14 (3) GROUP HEALTH PLAN.—The term ‘‘group

15 health plan means any employee welfare benefit
16 plan, governmental plan, or church plan (as defined
17 under paragraphs (1), (32), and (33) of section 3 of

18 the Employee Retirement Income Security Act of
19 1974) that provides or pays for medical benefits

20 whether directly, through insurance, or otherwise.
21 (4) HEALTH INSURANCE COVERAGE.—The term
22 ‘‘health insurance coverage’’ means a contractual ar-

23 rangement for the provision of, or payment for,
24 health care, including any arrangement consisting of

25 a hospital or medical expense incurred policy or cer-

9

•HR 4008 IH

1 tificate, hospital or medical service plan contract, or
2 health maintenance organization subscriber contract

3 and including such an arrangement in connection
4 with a group health plan.
5 (5) INSURER.—The term ‘‘insurer’’ means an

6 insurance company, insurance service, or insurance
7 organization (including a health maintenance organi-

8 zation) which is licensed to engage in the business
9 of insurance in a State and which is subject to State
10 law which regulates insurance (within the meaning

11 of section 514(b)(2)) and which provides health in-
12 surance coverage. Such term does not include a

13 group health plan.
14 (6) PARTICIPANT; BENEFICIARY.—The terms
15 ‘‘participant’’ and ‘‘beneficiary’’ have the meanings

16 given such terms in paragraphs (7) and (8), respec-
17 tively, of section 3 of the Employee Retirement In-

18 come Security Act of 1974.
19 (7) SECRETARY.—Except as specifically pro-
20 vided, the term ‘‘Secretary’’ means the Secretary of

21 Health and Human Services.
22 (8) STATE.—The term ‘‘State’’ includes the

23 District of Columbia, Puerto Rico, the Northern
24 Mariana Islands, the Virgin Islands, American
25 Samoa, and Guam.

10

•HR 4008 IH

1 (g) AUTHORIZATION OF FUNDING UNDER ERISA.—
2 Section 508 of the Employee Retirement Income Security

3 Act of 1974 (29 U.S.C. 1138) is amended by inserting

4 ‘‘and under the Genetic Information Health Insurance

5 Nondiscrimination Act of 1996’’ before the period.

6 (h) EFFECTIVE DATE.—This section shall apply to
7 health insurance coverage offered or renewed and to group

8 health plans after the end of the 90-day period beginning

9 on the date of the enactment of this Act.
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