

104TH CONGRESS  
2D SESSION

# S. 1600

To establish limitations on health plans with respect to genetic information,  
and for other purposes.

---

## IN THE SENATE OF THE UNITED STATES

MARCH 7 (legislative day, MARCH 6), 1996

Mrs. FEINSTEIN (for herself and Mr. MACK) introduced the following bill;  
which was read twice and referred to the Committee on Labor and  
Human Resources

---

## A BILL

To establish limitations on health plans with respect to  
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 Fairness Act  
5 of 1996”.

6 **SEC. 2. DEFINITIONS.**

7 As used in this Act:

8 (1) FAMILY MEMBER.—The term “family mem-  
9 ber” means, with respect to an individual, another

1 individual related by blood to that individual or a  
2 spouse or adopted child of the individual.

3 (2) GENETIC INFORMATION.—The term “ge-  
4 netic information” means the information about  
5 genes, gene products or inherited characteristics that  
6 may be derived from an individual or a family mem-  
7 ber.

8 (3) GENETIC SERVICES.—The term “genetic  
9 services” means health services provided to obtain,  
10 assess, and interpret genetic information for diag-  
11 nostic and therapeutic purposes, and for genetic  
12 education and counseling.

13 (4) GENETIC TEST.—The term “genetic test”  
14 means a procedure that is generally accepted in the  
15 scientific and medical communities and that is per-  
16 formed for the purposes of identifying the presence,  
17 absence, or alternation of any gene or chromosome.

18 (5) HEALTH PLAN.—The term “health plan”  
19 means—

20 (A) a group health plan (as such term is  
21 defined in section 607 of the Employee Retire-  
22 ment Income Security Act of 1974 (29 U.S.C.  
23 1167)), and a multiple employer welfare ar-  
24 rangement (as defined in section 3(40) of such  
25 Act) that provides health insurance coverage; or

1 (B) any contractual arrangement for the  
 2 provision of a payment for health care, includ-  
 3 ing any health insurance arrangement or any  
 4 arrangement consisting of a hospital or medical  
 5 expense incurred policy or certificate, hospital  
 6 or medical service plan contract, or health  
 7 maintenance organization subscriber contract.

8 (6) INSURER.—The term “insurer” means—

9 (A) an insurance company, health care  
 10 service contractor, fraternal benefit organiza-  
 11 tion, insurance agent, third party adminis-  
 12 trator, insurance support organization or other  
 13 person subject to regulation under State health  
 14 insurance laws;

15 (B) a managed care organization; or

16 (C) an employee welfare benefit plan regu-  
 17 lated under the Employee Retirement Income  
 18 Security Act of 1974 (29 U.S.C. 1001 et seq.).

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

21 **SEC. 3. PROHIBITIONS.**

22 (a) GENETIC INFORMATION.—An insurer offering a  
 23 health plan may not—

24 (1) terminate, restrict, limit, or otherwise apply  
 25 conditions to coverage of an individual or family

1 member under the plan, or restrict the sale of the  
2 plan to an individual or family member;

3 (2) cancel or refuse to renew the coverage of an  
4 individual or family member under the plan;

5 (3) deny coverage or exclude an individual or  
6 family member from coverage under the plan;

7 (4) impose a rider that excludes coverage for  
8 certain benefits and services under the plan;

9 (5) establish differentials in premium rates or  
10 cost sharing for coverage under the plan; or

11 (6) otherwise discriminate against an individual  
12 or family member in the provision of health care;

13 on the basis of any genetic information concerning an indi-  
14 vidual or family member or on the basis of an individual's  
15 or family member's request for or receipt of genetic serv-  
16 ices.

17 (b) GENETIC TESTS.—An insurer offering a health  
18 plan may not require an applicant for coverage under the  
19 plan, or an individual or family member who is presently  
20 covered under the plan, to be the subject of a genetic test  
21 or to be subjected to questions relating to genetic informa-  
22 tion.

23 (c) NOTICE OF RIGHTS.—An insurer offering a  
24 health plan shall, in the enrollment information provided  
25 by the insurer concerning such plan, provide an enrollee

1 with a written statement disclosing the rights of the en-  
2 rollee under this Act. Such statement shall be in a form  
3 and manner that is noticeable to and understandable by  
4 an average enrollee.

5 (d) ENFORCEMENT.—

6 (1) PLANS OTHER THAN EMPLOYEE WELFARE  
7 BENEFIT PLANS.—The requirements established  
8 under subsections (a), (b), and (c) shall be enforced  
9 by the State insurance commissioner for the State  
10 involved or the official or officials designated by the  
11 State, except that in no case shall a State enforce  
12 such requirements as they relate to employee welfare  
13 benefit plans.

14 (2) EMPLOYEE WELFARE BENEFIT PLANS.—  
15 With respect to employee welfare benefit plans, the  
16 Secretary shall enforce the requirements established  
17 under subsections (a), (b), and (c) in the same man-  
18 ner as provided for under sections 502, 504, 506,  
19 and 510 of the Employee Retirement Income Secu-  
20 rity Act of 1974 (29 U.S.C. 1132, 1134, 1136, and  
21 1140).

22 (3) PRIVATE RIGHT OF ACTION.—A person  
23 may, after that person has exhausted all available  
24 administrative remedies, bring a civil action—

1 (A) to enjoin any act or practice which vio-  
2 lates subsection (a), (b), or (c);

3 (B) to obtain other appropriate equitable  
4 relief—

5 (i) to redress such violations; or

6 (ii) to require the Secretary of Health  
7 and Human Services to enforce any such  
8 subsections, or

9 (C) to obtain other legal relief, including  
10 monetary damages.

11 (4) JURISDICTION.—State courts of competent  
12 jurisdiction and district courts of the United States  
13 have concurrent jurisdiction of actions under this  
14 subsection. The district courts of the United States  
15 shall have jurisdiction, without respect to the  
16 amount in controversy or the citizenship of the par-  
17 ties, to grant the relief provided for in paragraph (3)  
18 in any action.

19 (5) VENUE.—For purposes of this subsection  
20 the venue provisions of section 1391 of title 28,  
21 United States Code, shall apply.

22 (6) REGULATIONS.—The Secretary may pro-  
23 mulgate such regulations as may be necessary or ap-  
24 propriate to carry out this section.

1 **SEC. 4. EFFECTIVE DATE.**

2       This Act shall apply to any health plan offered or  
3 renewed on or after the end of the 90-day period beginning  
4 on the date of the enactment of this Act.

○