

105TH CONGRESS
1ST SESSION

H. R. 341

To establish limitations with respect to the disclosure and use of genetic information, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JANUARY 7, 1997

Mr. STEARNS (for himself, Mr. STUMP, Mr. TAYLOR of North Carolina, Mr. CALVERT, Mr. FALEOMAVAEGA, Mr. OBERSTAR, Ms. LOFGREN, Mr. MINGE, Mr. WATT of North Carolina, and Mr. OXLEY) introduced the following bill; which was referred to the Committee on Commerce, and in addition to the Committees on Government Reform and Oversight and Education and the Workforce, 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, 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. FINDINGS AND PURPOSES.**

7 (a) FINDINGS.—Congress finds the following:

1 (1) The DNA molecule contains information
2 about an individual's probable medical future.

3 (2) Genetic information is uniquely private and
4 personal information that should not be disclosed
5 without the authorization of the individual.

6 (3) The improper disclosure of genetic informa-
7 tion can lead to significant harm to the individual,
8 including stigmatization and discrimination in areas
9 such as employment, education, health care and in-
10 surance.

11 (4) An analysis of an individual's DNA provides
12 information not only about an individual, but also
13 about the individual's parents, siblings and children.

14 (5) Current legal protections for genetic infor-
15 mation, tissue samples and DNA samples are inad-
16 equate to protect genetic privacy, and require fur-
17 ther attention.

18 (6) Laws for the collection, storage and use of
19 identifiable DNA samples and private genetic infor-
20 mation obtained from those samples are needed both
21 to protect individual privacy and to permit legitimate
22 genetic research.

23 (b) PURPOSES.—It is the purpose of this Act to—

24 (1) define the rights of individuals whose ge-
25 netic information is disclosed;

1 (2) define the circumstances under which an in-
2 dividual’s genetic information may be disclosed; and

3 (3) protect against discrimination by an insurer
4 or employer based upon an individual’s genetic infor-
5 mation.

6 **SEC. 3. DEFINITIONS.**

7 As used in this Act:

8 (1) DNA.—The term “DNA” means
9 deoxyribonucleic acid.

10 (2) DNA SAMPLE.—The term “DNA sample”
11 means any human biological specimen from which
12 DNA can be extracted, or the DNA extracted from
13 such specimen.

14 (3) EMPLOYER.—The term “employer” has the
15 same meaning given such term in section 3(d) of the
16 Fair Labor Standards Act of 1938 (29 U.S.C.
17 203(d)).

18 (4) GENETIC INFORMATION.—The term “ge-
19 netic information” means the information about
20 genes, gene products or inherited characteristics that
21 may derive from an individual or a family member.

22 (5) GENETIC TEST.—The term “genetic test”
23 means a test for determining the presence or ab-
24 sence of genetic characteristics in an individual, in-
25 cluding tests of nucleic acids such as DNA, RNA

1 and mitochondrial DNA, chromosomes or proteins in
2 order to diagnose a genetic characteristic.

3 (6) INSURER.—The term “insurer” means an
4 insurance company, health care service contractor,
5 fraternal benefit organization, insurance agent, third
6 party administrator, insurance support organization
7 or other person subject to regulation under State in-
8 surance laws. Such term includes self-funded health
9 plans and health plans regulated under the Em-
10 ployee Retirement Income Security Act of 1974 (29
11 U.S.C. 1001 et seq.).

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

14 **SEC. 4. REQUIREMENTS FOR DISCLOSURE OF GENETIC**
15 **INFORMATION.**

16 (a) PROHIBITION.—

17 (1) IN GENERAL.—Except as provided in para-
18 graph (2), regardless of the manner in which genetic
19 information was received, or of the source of such
20 information, including information received from an
21 individual, an entity may not disclose or be com-
22 pelled (by subpoena or any other means) to disclose
23 genetic information about an individual unless such
24 disclosure is specifically authorized by the individual
25 involved or the legal representative of the individual

1 through a written authorization which includes a de-
2 scription of the information being disclosed, the
3 name of the individual or entity to whom the dislo-
4 sure is being made, and the purpose of the dislo-
5 sure.

6 (2) EXCEPTIONS.—Notwithstanding paragraph
7 (1), genetic information concerning an individual
8 may be disclosed if such disclosure—

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

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

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

20 (D) is for the purpose of furnishing genetic
21 information relating to a decedent to the blood
22 relatives of the decedent for the purpose of
23 medical diagnosis; or

24 (E) is for the purpose of identifying bodies.

1 (b) APPLICATION OF SECTION.—The prohibitions of
2 this section shall apply to any redisclosure by any entity
3 after another entity has disclosed the genetic information.

4 **SEC. 5. PROHIBITION ON CERTAIN EMPLOYMENT PRACTICES.**
5

6 (a) DISCRIMINATION AS TO RIGHTS OR BENEFITS.—
7 No employer may seek to obtain, obtain, or use the genetic
8 information of an employee or a prospective employee, or
9 require a genetic test of an employee or prospective em-
10 ployee, to distinguish between or discriminate against or
11 restrict any right or benefit otherwise due or available to
12 the employee or prospective employee.

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

18 **SEC. 6. REQUIREMENTS RELATING TO INSURERS.**

19 (a) GENERAL PROHIBITION.—An insurer offering
20 health insurance may not use genetic information to re-
21 ject, deny, limit, cancel, refuse to renew, increase the rates
22 of, or otherwise affect health insurance.

23 (b) PROHIBITION ON INDUCEMENT.—With respect to
24 a genetic test conducted in accordance with subsection (c),

1 an insurer may not use such a genetic test as an induce-
2 ment for the purchase of insurance.

3 (c) PERMISSIBILITY OF TESTS.—If an insurer re-
4 quests that an applicant for insurance (other than an ap-
5 plicant for health insurance) take a genetic test in connec-
6 tion with an application for insurance, the use of the re-
7 sults of such test shall be disclosed to the applicant and
8 the insurer shall obtain the specific written authorization
9 of the applicant for such disclosure.

10 (d) APPLICATION.—This section shall apply only to
11 insurance policies issued on or after the date of enactment
12 of this Act, and to the renewal of policies issued before,
13 on, or after such date of enactment.

14 **SEC. 7. FURTHER RECOMMENDATION BY THE NATIONAL**
15 **BIOETHICS ADVISORY COMMISSION.**

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

20 (1) the development and implementation of
21 standards to provide increased protection for the col-
22 lection, storage, and use of identifiable DNA sam-
23 ples and genetic information obtained from those
24 samples; and

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

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