

106TH CONGRESS
1ST SESSION

H. R. 1445

To promote research into, and the development of an ultimate cure for,
the disease known as fragile X.

IN THE HOUSE OF REPRESENTATIVES

APRIL 15, 1999

Mr. DELAHUNT (for himself and Mr. WATKINS) introduced the following bill;
which was referred to the Committee on Commerce

A BILL

To promote research into, and the development of an
ultimate cure for, the disease known as fragile X.

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 “Fragile X Research
5 Breakthrough Act of 1999”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds as follows:

8 (1) Fragile X is the most common inherited
9 cause of mental retardation. It affects one in every

1 2,000 boys and one in every 4,000 girls. One in 260
2 women is a carrier.

3 (2) Most children with fragile X require a life-
4 time of special care at a cost of over two million dol-
5 lars each.

6 (3) Relatively newly-discovered and relatively
7 unknown, even in the medical profession, fragile X
8 is caused by the absence of a single protein that can
9 be produced synthetically but that cannot yet be ef-
10 fectively assimilated.

11 (4) Fragile X research, both basic and applied,
12 is vastly underfunded in view of its prevalence, the
13 potential for the development of a cure, the estab-
14 lished benefits of currently available interventions,
15 and the significance that fragile X research has for
16 related disorders.

17 (5) Fragile X is a powerful research model for
18 other forms of X-linked mental retardation, as well
19 as neuropsychiatric disorders, including autism,
20 schizophrenia, mood disorders, and pervasive devel-
21 opmental disorder. Individuals with fragile X are a
22 homogeneous study population for advancing under-
23 standing of these disorders.

1 **SEC. 3. NATIONAL INSTITUTE OF CHILD HEALTH AND**
2 **HUMAN DEVELOPMENT; RESEARCH ON FRAG-**
3 **ILE X.**

4 Subpart 7 of part C of title IV of the Public Health
5 Service Act (42 U.S.C. 285g et seq.) is amended by adding
6 at the end the following section:

7 “FRAGILE X

8 “SEC. 452E. (a) EXPANSION AND COORDINATION OF
9 RESEARCH ACTIVITIES.—The Director of the Institute,
10 after consultation with the advisory council for the Insti-
11 tute, shall expand, intensify, and coordinate the activities
12 of the Institute with respect to research on the disease
13 known as fragile X.

14 “(b) RESEARCH CENTERS.—

15 “(1) IN GENERAL.—The Director of the Insti-
16 tute, after consultation with the advisory council for
17 the Institute, shall make grants to, or enter into
18 contracts with, public or nonprofit private entities
19 for the development and operation of centers to con-
20 duct research for the purposes of improving the di-
21 agnosis and treatment of, and finding the cure for,
22 fragile X.

23 “(2) NUMBER OF CENTERS.—In carrying out
24 paragraph (1), the Director of the Institute shall, to
25 the extent that amounts are appropriated, provide

1 for the establishment of at least three fragile X re-
2 search centers.

3 “(3) ACTIVITIES.—

4 “(A) IN GENERAL.—Each center assisted
5 under paragraph (1) shall, with respect to frag-
6 ile X—

7 “(i) conduct basic and clinical re-
8 search, which may include clinical trials
9 of—

10 “(I) new or improved diagnostic
11 methods; and

12 “(II) drugs or other treatment
13 approaches; and

14 “(ii) conduct research to find a cure.

15 “(B) FEES.—A center may use funds pro-
16 vided under paragraph (1) to provide fees to in-
17 dividuals serving as subjects in clinical trials
18 conducted under subparagraph (A).

19 “(4) COORDINATION AMONG CENTERS.—The
20 Director of the Institute shall, as appropriate, pro-
21 vide for the coordination of the activities of the cen-
22 ters assisted under this section, including providing
23 for the exchange of information among the centers.

24 “(5) CERTAIN ADMINISTRATIVE REQUIRE-
25 MENTS.—Each center assisted under paragraph (1)

1 shall use the facilities of a single institution, or be
 2 formed from a consortium of cooperating institu-
 3 tions, meeting such requirements as may be pre-
 4 scribed by the Director of the Institute.

5 “(6) DURATION OF SUPPORT.—Support may be
 6 provided to a center under paragraph (1) for a pe-
 7 riod not exceeding 5 years. Such period may be ex-
 8 tended for one or more additional periods, each of
 9 which may not exceed 5 years, if the operations of
 10 such center have been reviewed by an appropriate
 11 technical and scientific peer review group established
 12 by the Director and if such group has recommended
 13 to the Director that such period be extended.

14 “(7) AUTHORIZATION OF APPROPRIATIONS.—
 15 For the purpose of carrying out this subsection,
 16 there are authorized to be appropriated \$10,000,000
 17 for fiscal year 2000, and such sums as may be nec-
 18 essary for each subsequent fiscal year.”.

19 **SEC. 4. NATIONAL INSTITUTE OF CHILD HEALTH AND**
 20 **HUMAN DEVELOPMENT; LOAN REPAYMENT**
 21 **PROGRAM REGARDING RESEARCH ON FRAG-**
 22 **ILE X.**

23 Part G of title IV of the Public Health Service Act
 24 (42 U.S.C. 288 et seq.) is amended by inserting after sec-
 25 tion 487E the following section:

1 “LOAN REPAYMENT PROGRAM REGARDING RESEARCH ON
2 FRAGILE X

3 “SEC. 487F. (a) IN GENERAL.—The Secretary, in
4 consultation with the Director of the National Institute
5 of Child Health and Human Development, shall establish
6 a program under which the Federal Government enters
7 into contracts with qualified health professionals (includ-
8 ing graduate students) who agree to conduct research re-
9 garding fragile X in consideration of the Federal Govern-
10 ment’s agreement to repay, for each year of such service,
11 not more than \$35,000 of the principal and interest of
12 the educational loans owed by such health professionals.

13 “(b) APPLICABILITY OF CERTAIN PROVISIONS.—
14 With respect to the National Health Service Corps Loan
15 Repayment Program established in subpart III of part D
16 of title III, the provisions of such subpart (including sec-
17 tion 338B(g)(3)) shall, except as inconsistent with sub-
18 section (a) of this section, apply to the program estab-
19 lished in such subsection in the same manner and to the
20 same extent as such provisions apply to the National
21 Health Service Corps Loan Repayment Program estab-
22 lished in such subpart.

23 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the
24 purpose of carrying out this section, there are authorized
25 to be appropriated \$2,000,000 for fiscal year 2000, and

1 such sums as may be necessary for each subsequent fiscal
2 year. Amounts appropriated for a fiscal year under the
3 preceding sentence remain available until the expiration
4 of the second fiscal year beginning after the fiscal year
5 for which the amounts were appropriated.”.

