

116TH CONGRESS
1ST SESSION

H. R. 1131

To amend the Public Health Service Act to provide for the expansion, intensification, and coordination of the programs and activities of the National Institutes of Health with respect to Tourette syndrome.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 8, 2019

Mr. SIRES (for himself, Mr. ENGEL, Mr. COHEN, Mr. KHANNA, and Mr. SCHIFF) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to provide for the expansion, intensification, and coordination of the programs and activities of the National Institutes of Health with respect to Tourette syndrome.

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 “Collaborative Academic
5 Research Efforts for Tourette Syndrome Act of 2019”.

1 **SEC. 2. PROGRAMS OF THE NATIONAL INSTITUTES OF**
2 **HEALTH RELATING TO TOURETTE SYN-**
3 **DROME.**

4 Part B of title IV of the Public Health Service Act
5 is amended by inserting after section 409J (42 U.S.C.
6 284q) the following:

7 **“SEC. 409K. EXPANSION, INTENSIFICATION, AND COORDI-**
8 **NATION OF ACTIVITIES WITH RESPECT TO**
9 **TOURETTE SYNDROME.**

10 “(a) IN GENERAL.—The Secretary, acting through
11 the Director of NIH, shall expand, intensify, and coordi-
12 nate the programs and activities of the National Institutes
13 of Health with respect to scientific and clinical research
14 on Tourette syndrome.

15 “(b) DATA COLLECTION.—

16 “(1) SYSTEM.—In carrying out subsection (a),
17 the Secretary shall develop a system to collect data
18 on Tourette syndrome, including epidemiologic infor-
19 mation with respect to the incidence, prevalence, and
20 impact of Tourette syndrome in the United States.

21 “(2) BROAD AND NARROW DEFINITIONS.—The
22 data collection system under paragraph (1) shall
23 provide for the collection of primary data on
24 Tourette syndrome, including related data on the
25 various conditions known to be comorbid with
26 Tourette syndrome.

1 “(3) COLLECTION BY POPULATION AND GEO-
2 GRAPHICAL REGION.—The data collection system
3 under paragraph (1) shall provide for the collection
4 of data on the availability of medical and social serv-
5 ices for individuals with Tourette syndrome and
6 their families and the disaggregation of such data by
7 population and geographical region.

8 “(c) COLLABORATIVE RESEARCH CENTERS FOR
9 TOURETTE SYNDROME.—

10 “(1) IN GENERAL.—In carrying out subsection
11 (a), the Secretary shall award grants and contracts
12 to public or nonprofit private entities to pay all or
13 part of the cost of planning, establishing, improving,
14 and providing basic operating support for Collabo-
15 rative Research Centers for Tourette Syndrome.

16 “(2) RESEARCH.—Each center under para-
17 graph (1) shall conduct basic and clinical research
18 into Tourette syndrome. Such research should in-
19 clude investigations into the cause, diagnosis, early
20 detection, prevention, control, and treatment of
21 Tourette syndrome. The research conducted by such
22 centers, as a group, shall include research in the
23 fields of developmental neurobiology, neuroscience,
24 genetics, psychology, and pharmacology.

25 “(3) SERVICES FOR PATIENTS.—

1 “(A) IN GENERAL.—A center under para-
2 graph (1) may expend amounts provided under
3 such paragraph to carry out a program to make
4 individuals aware of opportunities to participate
5 as subjects in research conducted by the cen-
6 ters.

7 “(B) REFERRAL AND COSTS.—A program
8 under subparagraph (A) may, in accordance
9 with such criteria as the Secretary may estab-
10 lish, provide to the subjects described in such
11 subparagraph, referrals for health and other
12 services, and such patient care costs as are re-
13 quired for research.

14 “(C) AVAILABILITY AND ACCESS.—The ex-
15 tent to which a center can demonstrate avail-
16 ability and access to clinical services shall be
17 considered by the Secretary in decisions about
18 awarding grants and contracts to applicants
19 which meet the scientific criteria for funding
20 under this subsection.

21 “(4) ORGANIZATION OF COLLABORATIVE RE-
22 SEARCH CENTERS FOR TOURETTE SYNDROME.—

23 “(A) IN GENERAL.—A center under para-
24 graph (1) may—

1 “(i) use the facilities of a single insti-
2 tution; or

3 “(ii) be formed from a consortium of
4 cooperating institutions and patient advo-
5 cacy groups in order to maximize the scope
6 of the center’s services and geographic cov-
7 erage.

8 “(B) ELIGIBILITY REQUIREMENTS.—To be
9 eligible to make facilities so available (as de-
10 scribed in subparagraph (A)(i)) or participate
11 in such a consortium (as described in subpara-
12 graph (A)(ii)), an institution or group shall
13 meet such requirements as the Secretary may
14 prescribe.

15 “(5) NUMBER OF CENTERS; DURATION OF SUP-
16 PORT.—

17 “(A) IN GENERAL.—Subject to the avail-
18 ability of appropriations, the Secretary shall
19 provide for the establishment of not fewer than
20 4 and not more than 6 centers under paragraph
21 (1).

22 “(B) GEOGRAPHICAL DISTRIBUTION.—The
23 Secretary shall—

24 “(i) ensure that each of the centers
25 established under paragraph (1) is located

1 in a different region of the United States
2 than other such centers; and

3 “(ii) encourage the formation of such
4 centers from a consortium of entities (as
5 described in paragraph (4)(A)(ii)) covering
6 multiple regions or States.

7 “(C) DURATION.—Support for a center es-
8 tablished under paragraph (1) may be provided
9 under this section for a period not to exceed 5
10 years. Such period may be extended for one or
11 more additional periods not exceeding 5 years if
12 the operations of such center have been re-
13 viewed and approved by an appropriate tech-
14 nical and scientific peer review group estab-
15 lished by the Secretary and if such group has
16 recommended to the Secretary that such period
17 should be extended.

18 “(d) RESEARCH ON SYMPTOMOLOGY AND TREAT-
19 MENT.—In carrying out subsection (a), the Secretary shall
20 award grants on a competitive, peer-reviewed basis for re-
21 search on—

22 “(1) the full range of symptomology within the
23 Tourette syndrome clinical spectrum; and

24 “(2) the efficacy of treatment options for par-
25 ticular patient subpopulations.

1 “(e) FUNDING.—Of the amounts made available to
2 carry out the programs and activities of the National In-
3 stitutes of Health for a fiscal year, the Secretary shall des-
4 ignate a portion of such amounts for carrying out the pro-
5 grams and activities of the National Institutes of Health
6 with respect to Tourette syndrome.”.

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