

113TH CONGRESS  
1ST SESSION

# H. R. 146

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.

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## IN THE HOUSE OF REPRESENTATIVES

JANUARY 3, 2013

Mr. SIRES introduced the following bill; which was referred to the Committee on Energy and Commerce

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## 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 2013”.

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 Tourette syndrome.

14 “(b) DATA COLLECTION.—

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

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

9           “(1) IN GENERAL.—In carrying out subsection  
10          (a), the Secretary shall make awards of grants and  
11          contracts to public or nonprofit private entities to  
12          pay all or part of the cost of planning, establishing,  
13          improving, and providing basic operating support for  
14          centers of excellence regarding research on Tourette  
15          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 centers, as a group, shall  
22          conduct research including the fields of developmen-  
23          tal neurobiology, genetics, and psychopharmacology.

24          “(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 to applicants which meet the  
19          scientific criteria for funding under this section.

20          “(4) ORGANIZATION OF CENTERS.—

21                 “(A) IN GENERAL.—A center under para-  
22                 graph (1) may—

23                         “(i) use the facilities of a single insti-  
24                         tution; or

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

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

13 “(5) NUMBER OF CENTERS; DURATION OF SUP-  
14 PORT.—

15 “(A) IN GENERAL.—Subject to the avail-  
16 ability of appropriations, the Secretary shall  
17 provide for the establishment of not fewer than  
18 four and not more than six centers under para-  
19 graph (1).

20 “(B) GEOGRAPHICAL DISTRIBUTION.—The  
21 Secretary shall—

22 “(i) ensure that each of the centers  
23 established under paragraph (1) is located  
24 in a different region of the United States  
25 than the other such centers; and

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

5 “(C) DURATION.—Support for a center es-  
6 tablished under paragraph (1) may be provided  
7 under this section for a period of not to exceed  
8 5 years. Such period may be extended for one  
9 or more additional periods not exceeding 5  
10 years if the operations of such center have been  
11 reviewed by an appropriate technical and sci-  
12 entific peer review group established by the Sec-  
13 retary and if such group has recommended to  
14 the Secretary that such period should be ex-  
15 tended.

16 “(d) RESEARCH ON SYMPTOMOLOGY AND TREAT-  
17 MENT.—In carrying out subsection (a), the Secretary shall  
18 award grants on a competitive basis for research on—

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

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

23 “(e) FUNDING.—Of the amounts made available to  
24 carry out the programs and activities of the National In-  
25 stitutes of Health for a fiscal year, the Secretary shall des-

- 1 designate a portion of such amounts for carrying out the pro-
- 2 grams and activities of the National Institutes of Health
- 3 with respect to Tourette syndrome.”.

