

112TH CONGRESS
2D SESSION

S. _____

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 SENATE OF THE UNITED STATES

Mr. MENENDEZ (for himself and Mr. AKAKA) introduced the following bill; which was read twice and referred to the Committee on

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 2012”.

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 shall include
19 investigations into the cause, diagnosis, early detec-
20 tion, prevention, control, and treatment of Tourette
21 syndrome. The centers, as a group, shall conduct
22 multidisciplinary research in the fields of develop-
23 mental neurobiology, psychology, genetics, pharma-
24 cology, psychopharmacology, and neuroimaging.

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 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 advo-
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 4 and not more than 6 centers under paragraph
19 (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 igrate 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.”.