H. R. 619

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

JANUARY 28, 2015

Mr. SIRES 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 2015”.


SEC. 2. PROGRAMS OF THE NATIONAL INSTITUTES OF HEALTH RELATING TO TOURETTE SYNDROME.

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

"SEC. 409K. EXPANSION, INTENSIFICATION, AND COORDINATION OF ACTIVITIES WITH RESPECT TO TOURETTE SYNDROME.

"(a) IN GENERAL.—The Secretary, acting through the Director of NIH, shall expand, intensify, and coordinate the programs and activities of the National Institutes of Health with respect to scientific and clinical research on Tourette syndrome.

"(b) DATA COLLECTION.—

"(1) SYSTEM.—In carrying out subsection (a), the Secretary shall develop a system to collect data on Tourette syndrome, including epidemiologic information with respect to the incidence, prevalence, and impact of Tourette syndrome in the United States.

"(2) WIDE AND NARROW DEFINITIONS.—The data collection system under paragraph (1) shall provide for the collection of primary data on Tourette syndrome, including related data on the various conditions known to be comorbid with Tourette syndrome."
“(3) Collection by Population and Geographical Region.—The data collection system under paragraph (1) shall provide for the collection of data on the availability of medical and social services for individuals with Tourette syndrome and their families and the disaggregation of such data by population and geographical region.

“(c) Collaborative Research Centers for Tourette Syndrome.—

“(1) In General.—In carrying out subsection (a), the Secretary shall award grants and contracts to public or nonprofit private entities to pay all or part of the cost of planning, establishing, improving, and providing basic operating support for Collaborative Research Centers for Tourette Syndrome.

“(2) Research.—Each center under paragraph (1) shall conduct basic and clinical research into Tourette syndrome. Such research should include investigations into the cause, diagnosis, early detection, prevention, control, and treatment of Tourette syndrome. The research conducted by such centers, as a group, shall include research in the fields of developmental neurobiology, neuroscience, genetics, psychology, and pharmacology.

“(3) Services for Patients.—
“(A) IN GENERAL.—A center under paragraph (1) may expend amounts provided under such paragraph to carry out a program to make individuals aware of opportunities to participate as subjects in research conducted by the centers.

“(B) REFERRAL AND COSTS.—A program under subparagraph (A) may, in accordance with such criteria as the Secretary may establish, provide to the subjects described in such subparagraph, referrals for health and other services, and such patient care costs as are required for research.

“(C) AVAILABILITY AND ACCESS.—The extent to which a center can demonstrate availability and access to clinical services shall be considered by the Secretary in decisions about awarding grants and contracts to applicants which meet the scientific criteria for funding under this subsection.

“(4) ORGANIZATION OF COLLABORATIVE RESEARCH CENTERS FOR TOURETTE SYNDROME.—

“(A) IN GENERAL.—A center under paragraph (1) may—
“(i) use the facilities of a single institution; or

“(ii) be formed from a consortium of cooperating institutions and patient advocacy groups in order to maximize the scope of the center’s services and geographic coverage.

“(B) ELIGIBILITY REQUIREMENTS.—To be eligible to make facilities so available (as described in subparagraph (A)(i)) or participate in such a consortium (as described in subparagraph (A)(ii)), an institution or group shall meet such requirements as the Secretary may prescribe.

“(5) NUMBER OF CENTERS; DURATION OF SUPPORT.—

“(A) IN GENERAL.—Subject to the availability of appropriations, the Secretary shall provide for the establishment of not fewer than 4 and not more than 6 centers under paragraph (1).

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

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

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

“(C) DURATION.—Support for a center established under paragraph (1) may be provided under this section for a period of not to exceed 5 years. Such period may be extended for one or more additional periods not exceeding 5 years if the operations of such center have been reviewed and approved by an appropriate technical and scientific peer review group established by the Secretary and if such group has recommended to the Secretary that such period should be extended.

“(d) RESEARCH ON SYMPTOMOLOGY AND TREATMENT.—In carrying out subsection (a), the Secretary shall award grants on a competitive, peer-reviewed basis for research on—

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

“(2) the efficacy of treatment options for particular patient subpopulations.
“(e) FUNDING.—Of the amounts made available to carry out the programs and activities of the National Institutes of Health for a fiscal year, the Secretary shall designate a portion of such amounts for carrying out the programs and activities of the National Institutes of Health with respect to Tourette syndrome.”.