Collaborative Academic Research Efforts for Tourette Syndrome Act of 2015 (HR 619, 114th Congress)

Expands, intensifies, coordinates, and provides funding for research on Tourette syndrome by the National Institutes of Health (NIH).

Updated last July 6, 2016
for the 1/28/15 version of H.R. 619

WHAT IT DOES

This legislation aims to encourage and increase government and public coordination and research in regards to Tourette syndrome.

H.R. 619 would amend Part B of title IV of the Public Health Service Act. This amendment would require the Secretary of Health and Human Services to coordinate with the Director of NIH to:

- Develop a system for collection of data about Tourette syndrome incidence, prevalence and impact as well as available medical and social services for Tourette’s, and categorize the data based on population and geographical region.
- Provide grants and contracts to public and nonprofit organizations to create four to six regional Collaborative Research Centers for Tourette syndrome:
  - Centers may be single organizations or a consortium of institutions and patient advocacy groups and must be located in different regions of the U.S.
  - Center activities must include:
    - Conducting basic clinical research on the cause, symptoms, diagnosis, early detection, treatment, prevention, and control of Tourette syndrome; and
    - Advertising research studies to patients and providing subjects with referrals and clinical services.
- Award competitive research grants that focus on Tourette syndrome’s symptoms and effective treatments.
- Reallocate a portion of annual NIH funding to these programs and activities dedicated toward Tourette syndrome.

RELEVANT SCIENCE

Tourette syndrome is a neurodevelopmental disorder, resulting from deficits in the development of motor skills during childhood. Current estimates state that Tourette syndrome affects 0.3-0.6% (3 to 6 in 1000) of school aged children (ages 5-17). Symptoms of Tourette often improve into adolescence. The prevalence of newly diagnosed or existing Tourette’s syndrome in adults is largely unknown. The causes of Tourette syndrome remain unknown but the disease is hereditary and related to complex genetic factors. Due to the present developmental defects and sometimes as a result of symptoms, Tourette syndrome often occurs concurrently with other neuropsychiatric or neurodevelopmental conditions such as ADHD, autism spectrum disorder and oppositional defiant or conduct disorders.

Tourette syndrome is more specifically classified as a neuropsychiatric tic disorder. Tic disorder symptoms often include repetitive, involuntary verbalization and movements. A Tourette syndrome diagnosis is characterized by at least one verbal tic (sniffing, grunting, shouting, words and phrases, etc.) and at least two motor tics (blinking, grimacing, shrugging, etc.) over the minimum duration of one year.

ENDORSEMENTS & OPPOSITION

Endorsements:
H.R. 619 is endorsed by the Tourette Syndrome Association (TSA), who stated in a press release that they “collaborated with the New Jersey Center for Tourette Syndrome and Associated Disorders (NJCTS) and with Congressman Albio Sires and Senator Robert Menendez to reintroduce and lead the Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act in the 114th Congress.”

Opposition:

- At present, there has not been publicly reported opposition to this bill.

STATUS

H.R. 619 was introduced on January 28, 2015 and assigned to the House Energy and Commerce committee, more specifically to the Subcommittee on Health.

RELATED POLICIES

An identical bill, S. 276, also titled “Collaborative Academic Research Efforts for Tourette Syndrome Act of 2015” was introduced to the Senate on January 28, 2015. It was referred to the Committee on Health, Education, Labor, and Pensions. An identical bill, S. 276, also titled “Collaborative Academic Research Efforts for Tourette Syndrome Act of 2015” was introduced to the Senate on January 28, 2015. It was referred to the Committee on Health, Education, Labor, and Pensions.

POLICY HISTORY

Prior versions of this bill have been introduced in the 112th (H.R. 3760) and 113th (H.R. 146 and H.R. 4221) Congressional sessions.

SPONSORS

HR 619 is sponsored by Albio Sires (D-NJ).

PRIMARY AUTHOR

Michelle Zhu

EDITOR(S)

Allison Roder, PhD Candidate & Aubrey Incorvaia, MPP

RECOMMENDED CITATION