Collaborative Partnerships for the Tourette Syndrome Community 908.575.7350

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CARE ACT for Tourette Syndrome Reintroduced by Senator Menendez and Congressman Sires

Jersey-initiated legislation hailed by NJ Center for TS

January 28, 2015 – Somerville, NJ – The New Jersey Center for Tourette Syndrome and Associated Disorders, Inc. (NJCTS) is pleased to announce reintroduction of federal legislation to expand and further coordinate efforts towards research of Tourette Syndrome. The Collaborative Academic Research Efforts (CARE) Act for Tourette Syndrome, sponsored by Congressman Albio Sires (NJ-8) and Senator Bob Menendez (D-NJ), would promote activities at the National Institutes of Health (NIH) aimed at combating and diagnosing Tourette Syndrome (TS).

"The Center is actively seeking support for this critical legislation," said NJCTS Executive Director Faith W. Rice, "As many as 1 in 100 Americans are living with TS and their ability to thrive depends on highly qualified and expedited research."

Originally introduced by NJ Congressman Albio Sires in December 2011, with a Companion Bill introduced in the Senate by NJ Senator Robert Menendez shortly thereafter, the CARE Act amends the Public Health Service Act for the expansion, intensification and coordination of the programs and activities of the National Institutes of Health with respect to scientific and clinical research on Tourette Syndrome. The CARE Act does not authorize any new funding for TS, but rather reallocates existing funds towards new programs to more effectively research and collect data on TS.

TS is a neurological disorder characterized by involuntary sounds or movements known as tics. There is no cure, and the majority of people living with TS also suffer concurrent mental health disorders.

"Tourette syndrome continues to be a misunderstood disorder that is too often stigmatized, I am eager to reintroduce legislation that will work towards helping the lives of those affected by this syndrome" stated Congressman Sires. "While symptoms can be suppressed overtime, too many individuals, particularly children, face the everyday challenge of trying to manage tics whether at school or in various social settings. Expanded and collaborative research can teach us more about the cause and treatment of the disorder to help improve the lives of those individuals impacted by Tourette syndrome."

"Today, we reintroduce the CARE for Tourette Syndrome Act to reinforce our commitment of increasing awareness and attention to combat this condition," said Senator Menendez. "This legislation aims to expand our research efforts into this commonly misdiagnosed and misunderstood disease, allowing us to provide families and individuals with TS the security and peace of mind they desperately need – knowing we will continue to build on the progress already made at research centers like the one at Rutgers University, to better the lives of

those it affects. I look forward to working together with both the House and the Senate to find solutions that ensure this important bill is able to become law."

The Act would require the NIH to award grants and contracts to academic, healthcare and other institutions to support the establishment of four to six Collaborative Tourette Syndrome Research Centers in different regions of the country. These centers will host high level, concerted, scientific and clinical research into TS and related disorders.

Lastly, it would facilitate the collection of important data on various aspects of TS which can be used to provide a better understanding of the disorder, and assist with the development of programs and strategies aimed at advancing the TS research agenda.

NJCTS is collaborating with the Tourette Syndrome Association to ensure this initiative receives sponsorship across the country. Both agencies are urging members to write to their local elected officials asking them to support the bill.

NJCTS was established in 2004 as the nation's first Center of Excellence for Tourette Syndrome, providing services for families, outreach and support to the education and medical communities and support for collaborative research into better treatments and a cure for Tourette Syndrome. For more information about NJCTS, or how you can support the CARE Act for TS, visit www.njcts.org or call 908-575-7350.

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