



New Jersey Center for Tourette Syndrome
AND ASSOCIATED DISORDERS

*Collaborative Partnerships
for the Tourette Syndrome Community*

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CARE Act for Tourette Syndrome Reintroduced by NJ Congressman Albio Sires

New Jersey Center for Tourette Syndrome Supports this Critical Bill

May 28, 2014 – Somerville, NJ – The New Jersey Center for Tourette Syndrome is actively garnering support for the passage of a critical bill, the Collaborative Academic Research Efforts (CARE) for Tourette Syndrome Act of 2014 (H.R. 4221). The CARE Act represents an exciting opportunity for the entire TS community—calling on our government to stimulate research to increase understanding of and improve treatment for Tourette Syndrome. NJCTS is collaborating with the Tourette Syndrome Association to ensure this initiative receives sponsorship across the country.

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.

“I am pleased that the national Tourette Syndrome Association has joined with the New Jersey Center for Tourette Syndrome on the legislative effort to move forward the Collaborative Academic Research Efforts for Tourette Syndrome Act of 2014,” said Congressman Sires. “I introduced H.R. 4221 to improve the lives of individuals and families impacted by Tourette Syndrome through enhanced research efforts on the cause and cure for Tourette Syndrome. Since my days in the New Jersey state legislature, I have been proud to be supportive of NJCTS’s efforts to improve the quality of life of those affected by Tourette Syndrome in New Jersey. Now, in Congress, that progress is being made at the national level through the introduction of the CARE for Tourette Syndrome Act and I look forward to continuing the fight for better knowledge and care for Tourette Syndrome with both the assistance of NJCTS and TSA.” The Act would also 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.

“Similar government mandates have led to critical advances in other disorders. We believe the CARE Act will have significant impact in the field of TS,” said Annetta Hewko, TSA President. “Imagine the breadth and depth of TS research projects that could already be underway if these Collaborative TS Research Centers existed today! That is why we are collaborating with the New Jersey Center for Tourette Syndrome and Associated Disorders and committed to engaging TSA members across the country.”

“We are pleased that TSA has joined with us to create national awareness of this New Jersey initiated federal legislation that will ultimately make a difference in so many lives. We along with families from across our state and across the nation are grateful to Congressman Sires and Senator Menendez for their many years of advocacy on behalf of kids and families living with Tourette Syndrome,” said Faith W. Rice, NJCTS Executive Director. NJCTS and TSA are urging members to write to their local elected officials asking them to support the bill, with concerted efforts to do so during national Tourette Syndrome Awareness Month, May 15 through June 15.

About the national Tourette Syndrome Association

Marked by involuntary vocal sounds and physical movements called tics, Tourette Syndrome is an inherited neurological condition frequently misunderstood and misdiagnosed. Founded in 1972, the national Tourette Syndrome Association (TSA) is celebrating its 42nd year as the only national, voluntary health organization for people with Tourette Syndrome. The TSA strives to improve the lives of individuals and families living with TS by providing education, service and support, promoting research and advocating on behalf of the whole TS community. The TSA directs a network of 33 Chapters and more than 55 independent support groups across the country. For more information on TS, call 1-888-4-TOURET, visit <http://tsa-usa.org>, or find us on Facebook and Twitter.

About the New Jersey Center for Tourette Syndrome and Associated Disorders, Inc.

New Jersey Center for Tourette Syndrome and Associated Disorders, Inc. (NJCTS) was established in 2004 as the nation’s first Center of Excellence for Tourette Syndrome. NJCTS provides 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 the New Jersey Center for Tourette Syndrome and Associated Disorders call 908-575-7350, visit <http://njcts.org>, or find us on Facebook and Twitter.

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