Congress of the United States Washington, DC 20515

March 24, 2023

The Honorable Robert Aderholt Chairwoman House Appropriations Subcommittee on Labor, Health, Human Services, and Education United States House of Representatives 2358-B Rayburn House Office Building Washington, D.C. 20515 The Honorable Rosa DeLauro
Ranking Member
House Appropriations Subcommittee on
Labor, Health, Human Services and
Education
United States House of Representatives
2358-B Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Aderholt and Ranking Member DeLauro:

As members of Congress who are committed to improving the lives of children and adults with Tourette Syndrome in the United States, we respectfully request your support for continued funding at the enacted level of \$2.5 million in the Fiscal Year 2024 Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations bill for the continued funding of the Tourette Syndrome Public Health Education and Research Program at the Centers for Disease Control and Prevention, in partnership with the national Tourette Association of America.

Tourette Syndrome (TS) is a hereditary neurodevelopmental disorder that typically develops during childhood and persists into adulthood, making it a life-long condition for most individuals. The disorder affects children and adults in all racial and ethnic groups. The symptoms of this disorder are rapid, repeated, and involuntary movements and sounds called tics, which can range from mild to severe and disabling. People with TS and Tic Disorders often have other conditions, such as Attention Deficit Hyperactivity Disorder (ADHD) and Obsessive Compulsive Disorder (OCD). Tourette Syndrome is an often misunderstood and stigmatized disorder that impacts as many as 1 in 50 school aged children in the U.S. with Tourette Syndrome or another persistent Tic Disorder. Tourette Syndrome can have a profound, negative impact on the quality of life of those who are affected. The cause of the condition is unknown. There is no cure and treatment options are very limited.

In 2000, Congress passed the Children's Health Act (P.L. 106-310). This Act authorized the Tourette Syndrome Public Health, Education, and Research Outreach Program to increase recognition and diagnosis of Tourette Syndrome, decrease stigma attached to the disorder, and increase appropriate, effective treatment to those with Tourette Syndrome.

The program continues to successfully educate and train physicians, allied healthcare workers, and education professionals to ensure proper and timely diagnosis and treatment of children with Tourette Syndrome. The comprehensive epidemiological study of the disorder, also supported by

this program, will be critical for understanding and treating this disease. This study will seek to determine the prevalence of the disorder in the general population and the frequency of co-occurring disorders such as Attention Deficit Hyperactivity Disorder and Obsessive-Compulsive Disorder. The knowledge gained from this research will greatly improve the lives of children and adults with Tourette Syndrome.

We respectfully request that you include the enacted level of \$2.5 million for the Tourette Syndrome Public Health Education and Research Program at the Centers for Disease Control and Prevention in the FY2024 Labor HHS Appropriations bill.

We thank you and commend you for your leadership in ensuring an ongoing federal commitment to the improvement of health and the expansion of research, treatment, education, and prevention of diseases and disorders.

Sincerely,

Steve Cohen

Member of Congress

Zoe Lofgren

Member of Congress

Andrew R. Garbarino

Member of Congress

Bill Posey

Member of Congress

Brian Fitzpatrick

Member of Congress

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Take Auchincloss Member of Congress

Gerald E. Connolly
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Lloyd Doggett Member of Congress

Josh Gottheimer Member of Congress

Danny K. Davis Member of Congress Daniel T. Kildee
Member of Congress

Janiel T. Kiedes

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Glenn "GT" Thompson
Member of Congress

Julia Brownley
Member of Congress

Macc 9 3 8 C. Mark DeSaulnier

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Jimmy Panetta Member of Congress

James P. McGovern Member of Congress

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Nancy Mace Member of Congress Mary Gay Scanlon
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Brian Higgins
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Eric Swalwell

Member of Congress

Andy Kim

Member of Congress

Jan Schakowsky

Member of Congress

Stephen F. Lynch

Member of Congress

Dwight Evans

Member of Congress

Yared Golden

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Deborah K. Ross Member of Congress

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Emanuel Cleaver, II Member of Congress

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Member of Congress

Nanette Diaz Barragán
Member of Congress

Rashida Tlaib Member of Congress

Anna G. Eshoo Member of Congress Jesús G. "Chuy" García Member of Congress

David Kustoff
Member of Congress

Angie Craig

Member of Congress

Ami Bera, M.D. Member of Congress

Scott H. Peters Member of Congress Garret Graves
Member of Congress

Jefferson Van Drew Member of Congress

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Al Green

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Jahana Hayes

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Member of Congress

Lucy MCBath

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Andrea Salinas Member of Congress Robert C. "Bobby" Scott Member of Congress

Ilhan Omar

Member of Congress

Pete Sessions

Member of Congress

John B. Larson

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Dan Goldman

Member of Congress

Abigail Davis Spanberger

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Madeleine Dean

Member of Congress

Brad Sherman

Troy Carter Member of Congress