

April 25, 2022

The Honorable Rosa DeLauro
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 Tom Cole
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 DeLauro and Ranking Member Cole:

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 \$2.5 million in the Fiscal Year 2023 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 100 school aged children in the U.S. with Tourette Syndrome or another 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.

The program has been flat funded at \$2 million since Fiscal Year 2015. The additional \$500,000 would fund: 1) a systematic literature review to determine prevalence of TS and tic disorders, 2) a systematic literature review to document the impact and cost of TS and tic disorders, 3) small grants to pilot innovative approaches at Centers of Excellence (CoE) in 5-7 states to address priority needs including health equity, transition, and suicide prevention among families affected by TS and tic disorders through CoEs, and 4) two new Continuing Medical Education (CME) modules to serve U.S. providers to increase providers' ability to identify, diagnose and treat tics and tic disorders.

We respectfully request that you include \$2.5 million for the Tourette Syndrome Public Health Education and Research Program at the Centers for Disease Control and Prevention in the FY2023 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



Lee M. Zeldin
Member of Congress



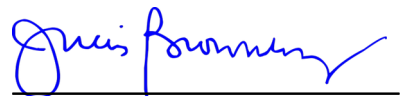
Zoe Lofgren
Member of Congress



Brian K. Fitzpatrick
Member of Congress



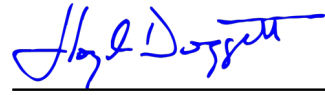
Michael F. Q. San Nicolas
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Julia Brownley
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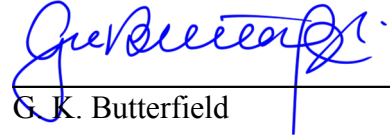
Antonio Delgado
Member of Congress



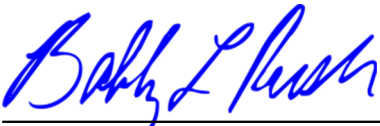
Lloyd Doggett
Member of Congress



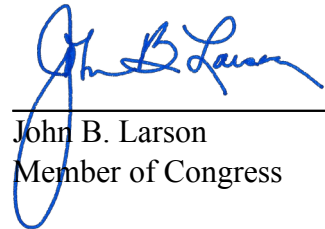
Carolyn B. Maloney
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G. K. Butterfield
Member of Congress



Bobby L. Rush
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John B. Larson
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Peter A. DeFazio
Member of Congress



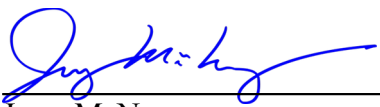
Joe Wilson
Member of Congress



Anthony Gonzalez
Member of Congress



Raúl M. Grijalva
Member of Congress



Jerry McNerney
Member of Congress



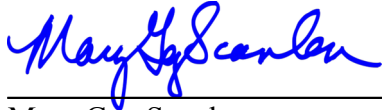
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Mark DeSaulnier
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Maria Elvira Salazar
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Mary Gay Scanlon
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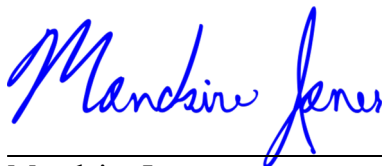
Deborah K. Ross
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Marilyn Strickland
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Madeleine Dean
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Mondaire Jones
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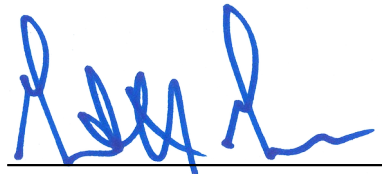
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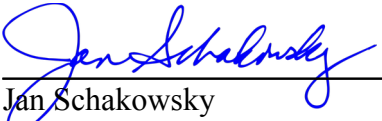
David B. McKinley P.E.
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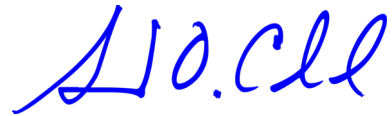
Eric Swalwell
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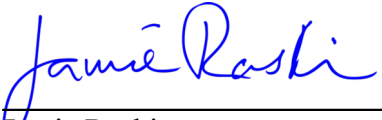
Stephen F. Lynch
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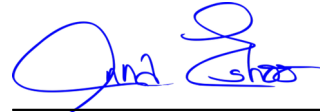
Tom Malinowski
Member of Congress



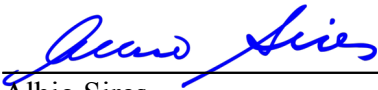
Kathy E. Manning
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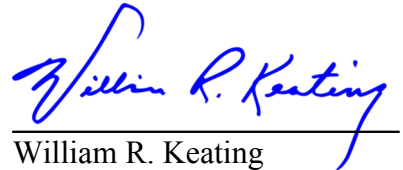
Michael Waltz
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Albio Sires
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William R. Keating
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Marc A. Veasey
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J. Luis Correa
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Vicente Gonzalez
Member of Congress



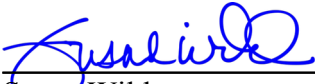
Chellie Pingree
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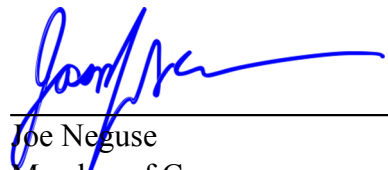
Jefferson Van Drew
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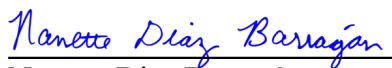
Joe Neguse
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Andy Kim
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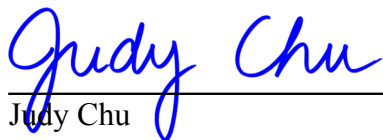
Pete Sessions
Member of Congress



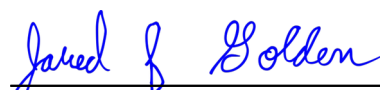
Nanette Diaz Barragán
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Elissa Slotkin
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Judy Chu
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Jared Golden
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Donald M. Payne, Jr.
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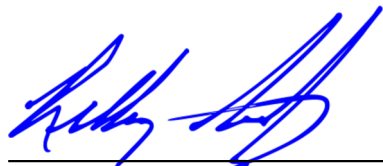
Terrold Nadler
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Mikie Sherrill
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Mike Thompson
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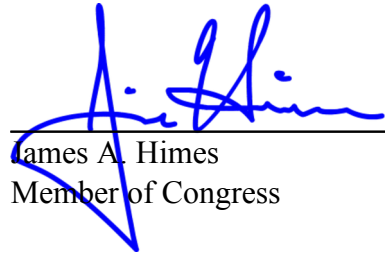
Kelly Armstrong
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Josh Gottheimer
Member of Congress



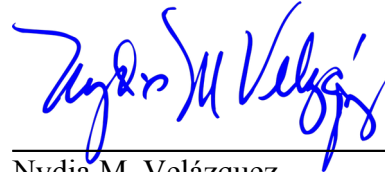
Emanuel Cleaver, II
Member of Congress



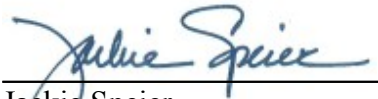
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Nydia M. Velázquez
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Jackie Speier
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Ami Bera, M.D.
Member of Congress



Colin Z. Allred
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Robert C. "Bobby" Scott
Member of Congress



Marie Newman
Member of Congress



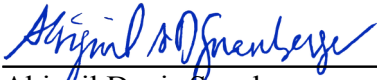
Kim Schrier, M.D.
Member of Congress



Lisa Blunt Rochester
Member of Congress



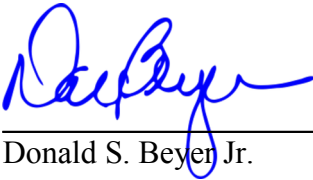
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Member of Congress



Abigail Davis Spanberger
Member of Congress



James Comer
Member of Congress



Donald S. Beyer Jr.
Member of Congress



Earl Blumenauer
Member of Congress



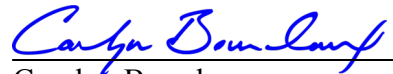
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Scott H. Peters
Member of Congress



Elaine G. Luria
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Carolyn Bourdeaux
Member of Congress



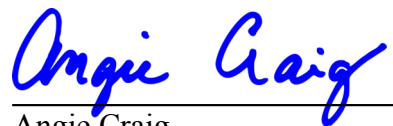
Young Kim
Member of Congress



Ilhan Omar
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Brad Sherman
Member of Congress



Angie Craig
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