Congress of the United States

Washington, DC 20515

March 29, 2023

The Honorable Ken Calvert (R-CA-42)
Chairman
Defense Subcommittee
U.S. House Committee on Appropriations
H-405 The Capitol
Washington, D.C. 20515

The Honorable Betty McCollum (D-MN-4)
Ranking Member
Defense Subcommittee
U.S. House Committee on Appropriations
1016 Longworth House Office Building
Washington, D.C. 20515

Dear Chairman Calvert and Ranking Member McCollum:

Rett syndrome (RTT) is the most severe neurologic disorder to affect females in childhood. Occurring in approximately 1 in every 10,000 female births and more rarely in males, it is caused by a mutation in the MECP2 gene, located on the X chromosome. Females have two X chromosomes; therefore, not all of their cells are affected by the mutation. This cellular "mosaicism" adds to the complexity of Rett syndrome research. Additionally, over two hundred different variants in the MECP2 gene have been associated with Rett syndrome.[1]

RTT is characterized by a loss of acquired fine and gross motor skills and the development of Neurological and autonomic dysfunction. Most children experience cardiac, respiratory, digestive, and muscular abnormalities. They are often unable to walk or talk, and many develop scoliosis and seizures. Those with RTT require lifelong care but can live well into adulthood.

In the United States, approximately 9,000 females are living with RTT. With no approved treatments, care providers can only rely on physical and occupational therapy, speech therapy, and seizure medications to manage the symptoms of disorder. As a rare disease, there are still no approved treatments available for those with Rett syndrome, and there is no cure. Rett syndrome needs federal funding support to best engage the research community.

Rett syndrome research often contributes to the understanding of and possible treatments of other synaptic brain disorders, such as Alzheimer's, Autism, Parkinson's, and traumatic brain injury.

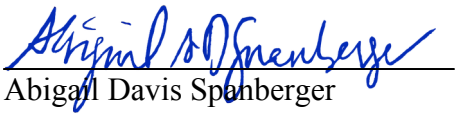
We respectfully request your support to include Rett syndrome as a research topic eligible for funding through the Peer Reviewed Medical Research Program (PRMRP) in the Fiscal Year 2024 Defense Appropriations bill. We make this request in honor of Brooke Mehta, a five-year-old girl from Virginia, who tragically passed away due to complications from RTT on March 25, 2021.

PRMRP funds are provided within the Congressionally Directed Medical Research Program (CDMRP) under the Defense Health Program. Listing Rett syndrome as a CDMRP topic in the FY24 Defense Appropriations bill will facilitate peer-reviewed research to ultimately help the thousands of families with a loved one living with this disease. Additionally, it would seem feasible that advancements made in these areas can also help servicemembers with service-connected disabilities who need lifelong care.

Thank you for your consideration of this request.

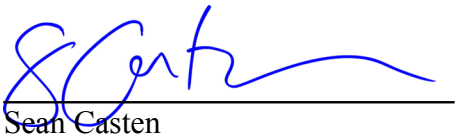
Sincerely,

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3880396/

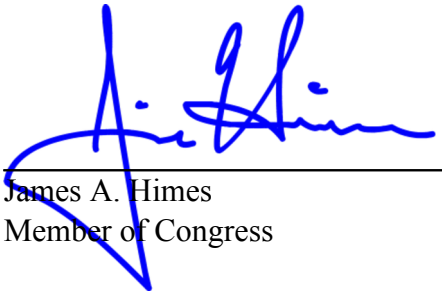


Abigail Davis Spanberger
Member of Congress

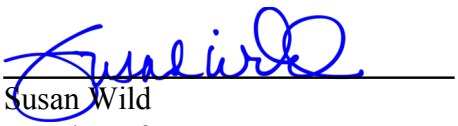
Brad R. Wenstrup, D.P.M.
Member of Congress



Sean Casten
Member of Congress



James A. Himes
Member of Congress



Susan Wild
Member of Congress

David Scott
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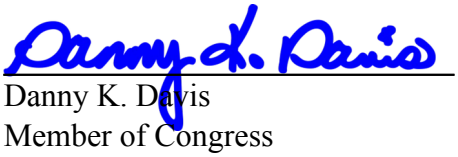
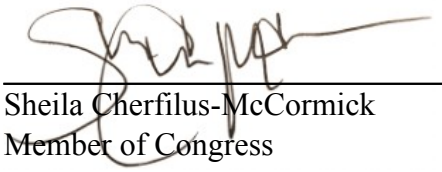
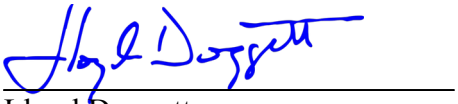


Danny K. Davis
Member of Congress



Sheila Cherfilus-McCormick
Member of Congress



Lloyd Doggett
Member of Congress

Eleanor Holmes Norton
Member of Congress