

United States Senate

WASHINGTON, DC 20510

April 9, 2019

Senator Richard Shelby
Chairman
Subcommittee on Defense
Committee on Appropriations
122 Senate Dirksen Building
Washington, DC 20510

Senator Richard Durbin
Ranking Member
Subcommittee on Defense
Committee on Appropriations
113 Senate Dirksen Building
Washington, DC 20510

Senator Roy Blunt
Chairman
Subcommittee on Labor-Health and
Human Services-Education
131 Senate Dirksen Building
Washington, DC 20510

Senator Patty Murray
Ranking Member
Subcommittee on Labor-Health and
Human Services-Education
156 Senate Dirksen Building
Washington, DC 20510

Dear Chairmen and Ranking Members:

We are writing to support a continuation of funding for Tuberous Sclerosis Complex (TSC) research in the fiscal year 2020 appropriations process, through the Tuberous Sclerosis Complex Research Program (TSCRP) and existing research initiatives at the National Institutes of Health (NIH).

Tuberous sclerosis complex (TSC) is a genetic condition that afflicts an estimated 50,000 Americans, causing tumors in the kidneys, lungs, liver, heart, eyes, skin, and brain. Researchers have linked TSC to seizures, autism spectrum disorder and severe intellectual disability. Research on TSC has proven to have a significant impact on our understanding of traumatic brain injury and other medical conditions like cancer and diabetes, and research at the TSCRP is critical to ongoing progress.

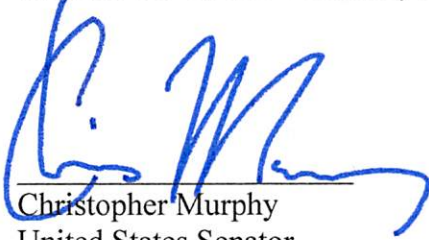
The TSCRP is a well-established program and has enjoyed bipartisan support from Congress. The program awards grants competitively to cutting edge research proposals aimed at gaining a better understanding of this complex disorder. Coordination between NIH and the Department of Defense (DoD) is managed by a trans-NIH working group, led by the National Institutes of Neurological Disorders and Strokes, with participation from eight separate Institutes, DoD and the Tuberous Sclerosis Alliance. This working group has achieved exemplary results with breakthroughs in TSC research leading to two FDA-approved indications for a drug that shrinks brain and kidney tumors associated with TSC.

While this research has led to significant breakthroughs, far more is needed if we hope to find ways to more effectively treat those who suffer with TSC and prevent its occurrence in future generations. Continued funding is required to support clinical studies to validate biomarkers and outcome measurements necessary to accelerate development of new

therapeutic agents, understand the biology underlying the wide variation in severity of manifestations among individuals with TSC. Furthermore, this investment is necessary to attract new researchers into this field of study, and to develop assays and animal models necessary for translating basic scientific discoveries into clinical treatments.

Ongoing support is necessary to move this research closer to ultimately finding a cure for tuberous sclerosis complex, and we urge you to appropriate funding necessary to continue the TSCRP in fiscal year 2020.

Sincerely,



Christopher Murphy
United States Senator



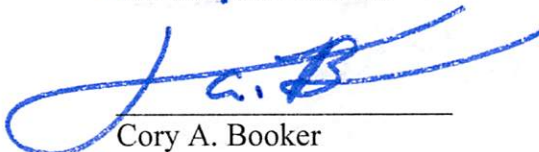
Johnny Isakson
United States Senator



Tammy Baldwin
United States Senator



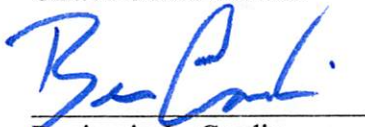
Richard Blumenthal
United States Senator



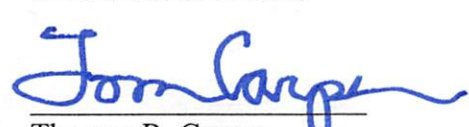
Cory A. Booker
United States Senator



Sherrod Brown
United States Senator



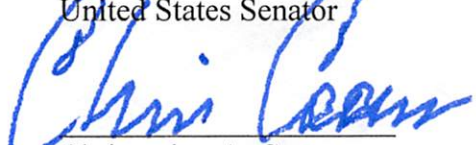
Benjamin L. Cardin
United States Senator



Thomas R. Carper
United States Senator



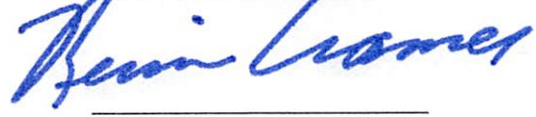
Susan M. Collins
United States Senator



Christopher A. Coons
United States Senator



Catherine Cortez Masto
United States Senator



Kevin Cramer
United States Senator



Tammy Duckworth
United States Senator



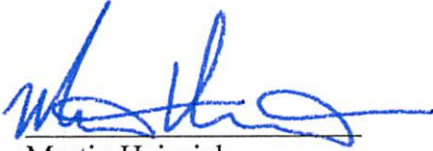
Dianne Feinstein
United States Senator



Kirsten E. Gillibrand
United States Senator



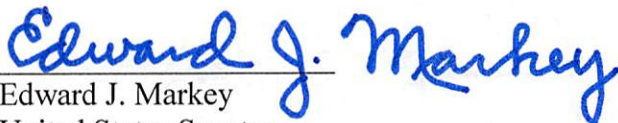
Kamala D. Harris
United States Senator



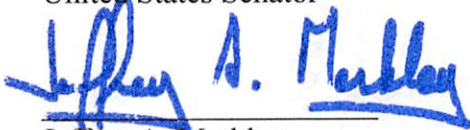
Martin Heinrich
United States Senator



Doug Jones
United States Senator



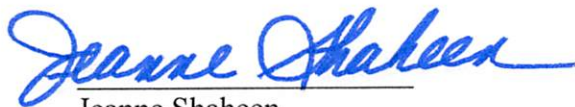
Edward J. Markey
United States Senator



Jeffrey A. Merkley
United States Senator



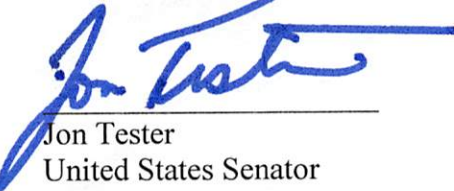
Jack Reed
United States Senator



Jeanne Shaheen
United States Senator



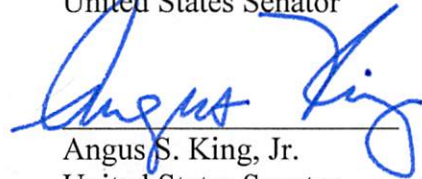
Debbie Stabenow
United States Senator



Jon Tester
United States Senator



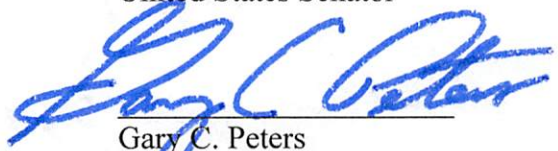
Mazie K. Hirono
United States Senator



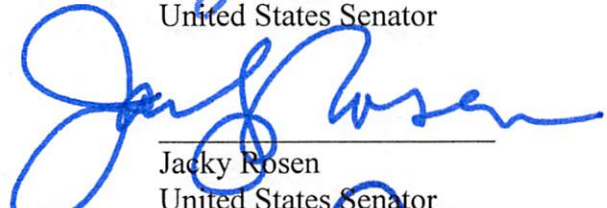
Angus S. King, Jr.
United States Senator



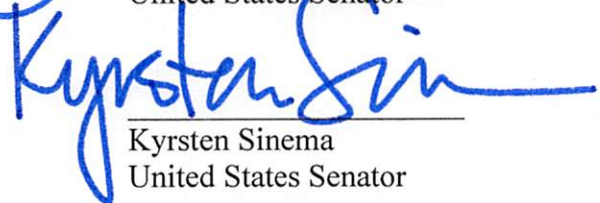
Robert Menendez
United States Senator



Gary C. Peters
United States Senator



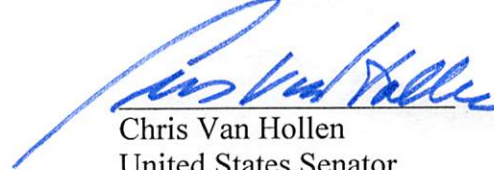
Jacky Rosen
United States Senator



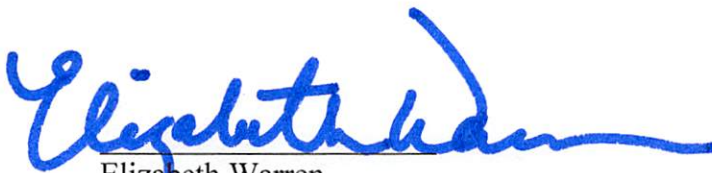
Kyrsten Sinema
United States Senator



Dan Sullivan
United States Senator



Chris Van Hollen
United States Senator



Elizabeth Warren
United States Senator



Sheldon Whitehouse
United States Senator



Ron Wyden
United States Senator