

# United States Senate

WASHINGTON, DC 20510

May 19, 2021

The Honorable Patty Murray  
Chairwoman  
Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
Senate Committee on Appropriations  
136 Dirksen Senate Office Building  
Washington, D.C. 20510

The Honorable Roy Blunt  
Ranking Member  
Subcommittee on Labor, Health and Human  
Services, Education, and Related Agencies  
Senate Committee on Appropriations  
156 Dirksen Senate Office Building  
Washington, D.C. 20510

The Honorable Jon Tester  
Chairman  
Subcommittee on Defense  
Senate Committee on Appropriations  
122 Dirksen Senate Office Building  
Washington, D.C. 20510

The Honorable Richard C. Shelby  
Ranking Member  
Subcommittee on Defense  
Senate Committee on Appropriations  
115 Dirksen Senate Office Building  
Washington, D.C. 20510

Dear Chairs and Ranking Members:

We are writing to support a continuation of funding for Tuberous Sclerosis Complex (TSC) research in the fiscal year 2022 appropriations process, through the Tuberous Sclerosis Complex Research Program (TSCRCP) at the Department of Defense (DoD) 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 TSCRCP is critical to ongoing progress.

The TSCRCP 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. Research supported by the TSCRCP complements – and does not duplicate – ongoing studies on TSC supported by the NIH. Coordination between NIH and the TSCRCP is managed by a trans-NIH working group, led by the National Institute of Neurological Disorders and Stroke, with participation from eight separate Institutes, DoD and the Tuberous Sclerosis Alliance, representing the patient community. This working group has

achieved exemplary results with breakthroughs in TSC research leading to two FDA-approved medications to shrink tumors in the brain and kidney and to treat seizures associated with TSC.

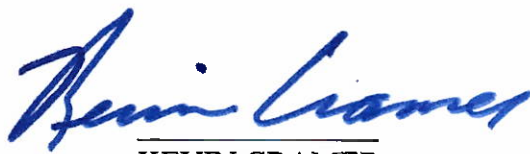
While this research has led to significant breakthroughs, far more is needed if we hope to find ways to more effectively treat those who suffer with TSC and prevent its occurrence in future generations. In fiscal year 2020, there was only enough research funding available to fund 25.6 percent of the research proposals received by the TSCRP. 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, attract new researchers into this field of study, identify potential biomarkers that can be applied to newborn screening and 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 2022

Sincerely,



MARTIN HEINRICH  
United States Senator



KEVIN CRAMER  
United States Senator

/s/ Richard Blumenthal  
RICHARD BLUMENTHAL  
United States Senator

/s/ Michael F. Bennet  
MICHAEL F. BENNET  
United States Senator

/s/ Catherine Cortez Masto  
CATHERINE CORTEZ MASTO  
United States Senator

/s/ Tammy Duckworth  
TAMMY DUCKWORTH  
United States Senator

/s/ Thomas R. Carper  
THOMAS R. CARPER  
United States Senator

/s/ Sherrod Brown  
SHERROD BROWN  
United States Senator

/s/ Sheldon Whitehouse  
SHELDON WHITEHOUSE  
United States Senator

/s/ Jacky Rosen  
JACKY ROSEN  
United States Senator

/s/ Kirsten E. Gillibrand  
KIRSTEN E. GILLIBRAND  
United States Senator

/s/ Tammy Baldwin  
TAMMY BALDWIN  
United States Senator

/s/ Angus S. King, Jr.  
ANGUS S. KING, JR.  
United States Senator

/s/ Elizabeth Warren  
ELIZABETH WARREN  
United States Senator

/s/ Edward J. Markey  
EDWARD J. MARKEY  
United States Senator

/s/ Jeanne Shaheen  
JEANNE SHAHEEN  
United States Senator

/s/ Ron Wyden  
RON WYDEN  
United States Senator

/s/ Debbie Stabenow  
DEBBIE STABENOW  
United States Senator

/s/ Jeffrey A. Merkley  
JEFFREY A. MERKLEY  
United States Senator

/s/ Dan Sullivan  
DAN SULLIVAN  
United States Senator

/s/ Gary C. Peters  
GARY C. PETERS  
United States Senator

/s/ Chris Van Hollen  
CHRIS VAN HOLLEN  
United States Senator

/s/ Benjamin L. Cardin  
BENJAMIN L. CARDIN  
United States Senator

/s/ Robert Menendez  
ROBERT MENENDEZ  
United States Senator

/s/ Dianne Feinstein  
DIANNE FEINSTEIN  
United States Senator

/s/ Cory A. Booker  
CORY A. BOOKER  
United States Senator

/s/ Maria Cantwell  
MARIA CANTWELL  
United States Senator

/s/ Ben Ray Luján  
BEN RAY LUJÁN  
United States Senator

/s/ Alex Padilla  
ALEX PADILLA  
United States Senator

/s/ Mazie K. Hirono  
MAZIE K. HIRONO  
United States Senator

/s/ Mark Kelly  
MARK KELLY  
United States Senator

/s/ Amy Klobuchar  
AMY KLOBUCHAR  
United States Senator

/s/ Jack Reed  
JACK REED  
United States Senator

/s/ Kyrsten Sinema  
KYRSTEN SINEMA  
United States Senator