May 19, 2021

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

The Honorable Jon Tester The Honorable Richard C. Shelby
Chairman Ranking Member
Subcommittee on Defense Subcommittee on Defense
Senate Committee on Appropriations Senate Committee on Appropriations
122 Dirksen Senate Office Building 115 Dirksen Senate Office Building
Washington, D.C. 20510 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 (TSCRP) 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 affects 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. Research supported by the TSCRP complements – and does not duplicate – ongoing studies on TSC supported by the NIH. Coordination between NIH and the TSCRP 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 TSCR. 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 TSCR 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