United States Senate

WASHINGTON, DC 20510

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Senator Jon Tester
Chairman
Subcommittee on Defense
Committee on Appropriations
122 Senate Dirksen Building
Washington, DC 20510

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

Senator Tammy Baldwin
Chair
Subcommittee on Labor-Health and Human Services-Education
131 Senate Dirksen Building
Washington, DC 20510

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

Dear Chairs and Ranking Members:

We are writing in support of a continuation of funding for tuberous sclerosis complex (TSC) research in the Fiscal Year (FY) 2025 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). We are grateful for the past bipartisan support TSCRP has received, and look forward to continuing this support in FY 2025.

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 competitive grants to cutting edge research proposals aimed at gaining a better understanding of this complex disorder. Research supported by the TSCRP complements ongoing studies on TSC supported by the NIH, and is not duplicative. 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 TSC Alliance, who represents the TSC patient community. This working group has achieved exemplary results with breakthroughs in TSC research. This research has led to the development of three FDA-approved medications to shrink tumors in the brain, kidney, and skin and to treat seizures associated with TSC.

While this research has led to significant breakthroughs, far more funding 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 FY2023, 12 applications were selected for funding, but an additional 17 applications scored as Outstanding or Excellent were not funded, which totaled $8.6 million in

unfunded research. Continued funding is required to support clinical studies to validate biomarkers and outcome measurements necessary to accelerate development of new therapeutic agents. These studies will also help us understand the biology underlying the wide variation in severity of manifestations among individuals with TSC, explore gene therapy, 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 TSC, and we urge you to appropriate funding necessary to continue the TSCRP in FY 2025.

[[CLOSING]]

[[SIGNATURES]]