Congress of the United States Washington, DC 20515

April 28, 2021

The Honorable Betty McCollum Chair Subcommittee on Defense Committee on Appropriations H-405 Capitol Building Washington, DC 20515 The Honorable Ken Calvert Ranking Member Subcommittee on Defense Committee on Appropriations 1016 Longworth House Office Building Washington, DC 20515

Dear Chairwoman McCollum and Ranking Member Calvert:

As you begin to craft the Fiscal Year (FY) 2022 Department of Defense (DoD) Appropriations bill, we respectfully request that you maintain the current funding level of \$8 million, for the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense (DoD).

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 is also having a significant effect 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.

From FY 2002 to FY 2021, Congress appropriated an aggregate of \$97 million to the TSCRP. This well-established program, which has enjoyed bipartisan support from Congress, awards grants competitively to cutting edge research proposals aimed at gaining a better understanding of this complex disorder. Research at the TSCRP complements – and does not duplicate – ongoing studies on TSC supported by the National Institutes of Health (NIH). Coordination between NIH and DoD 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.

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 FY 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.

To date, patient organizations have invested more than \$27.7 million in privately raised resources to the research effort. Ongoing support is necessary to move this research closer to ultimately finding a cure for tuberous sclerosis complex.

We firmly believe that Congress should match these private sector commitments, and we urge you to appropriate \$8 million in necessary funding to continue the TSCRP in FY2022. We are extremely grateful that Congress provided an increase in fiscal year 2021, from \$6 million to \$8 million, and our request for FY 2022 asks the committee to maintain the TSCRP at this existing level.

Sincerely,

Jamie Raskin

Member of Congress

Markwayne Mullin

Member of Congress

Member of Congress

List of Signatories:

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