

Congress of the United States
Washington, DC 20515

April 1, 2019

The Honorable Pete Visclosky
Chairman
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
2205 Rayburn HOB
Washington, DC 20515

Dear Chairman Visclosky and Ranking Member Calvert:

We are writing to support a continuation of funding for Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense (DoD) in the fiscal year 2020 Defense Appropriations Act.

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 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.

From fiscal years 2002 to 2019, Congress appropriated an aggregate of \$83 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 fiscal year 2018, there was only enough research funding available to fund 23.2 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, and develop assays and animal models necessary for translating basic scientific discoveries into clinical treatments.

To date, patient organizations have invested more than \$20.7 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 funding necessary to continue the TSCRP in fiscal year 2020.

Sincerely,



Markwayne Mullin
Member of Congress



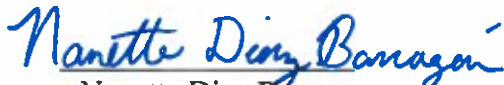
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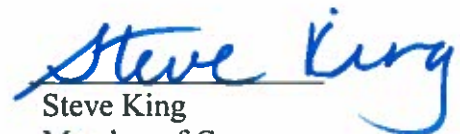
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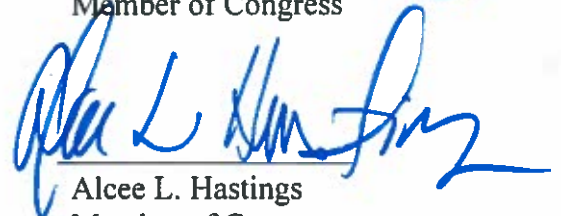
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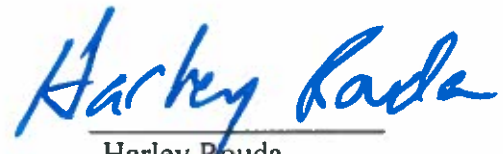

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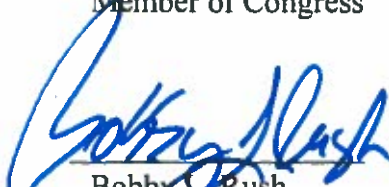

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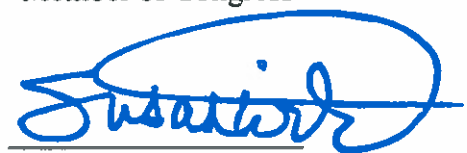

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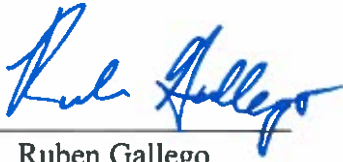

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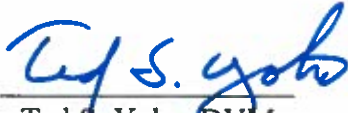
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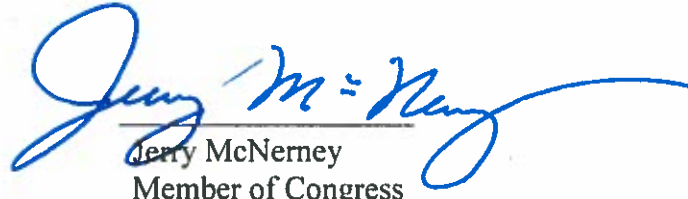
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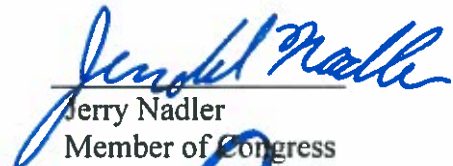
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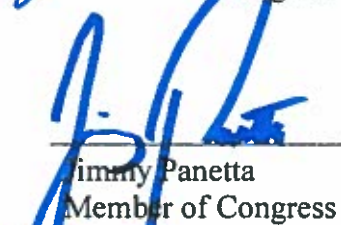
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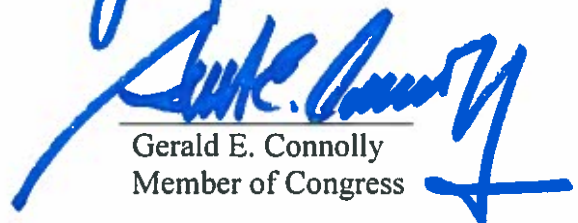
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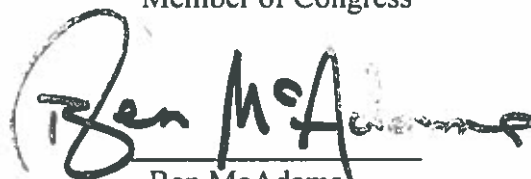
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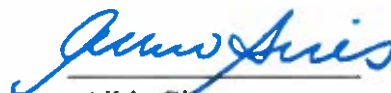
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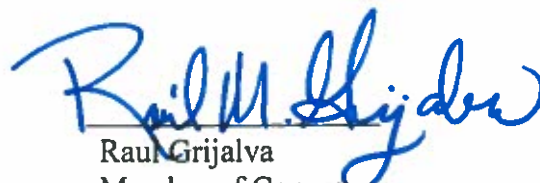
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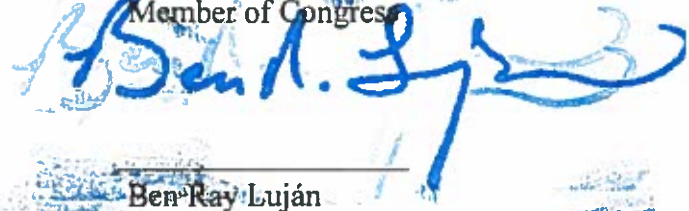
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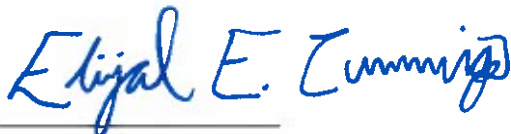
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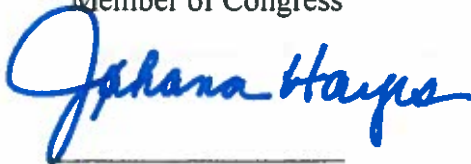
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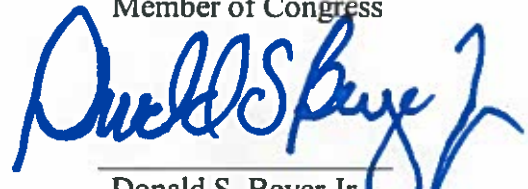

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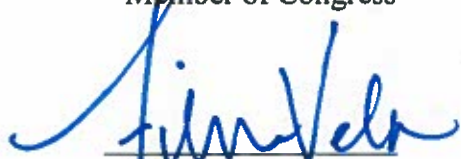
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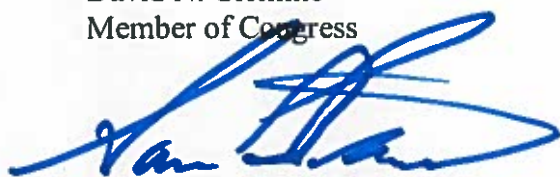
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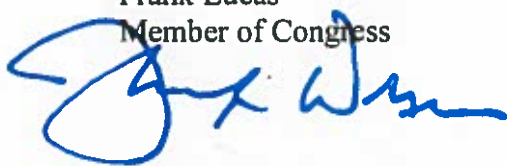
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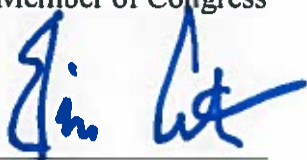
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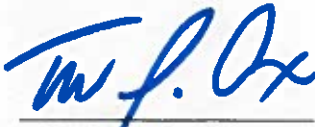
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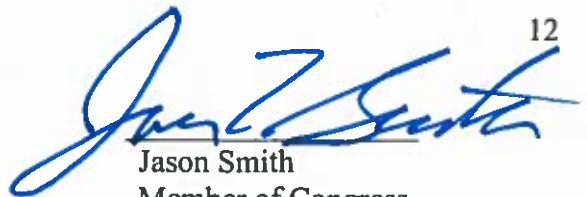
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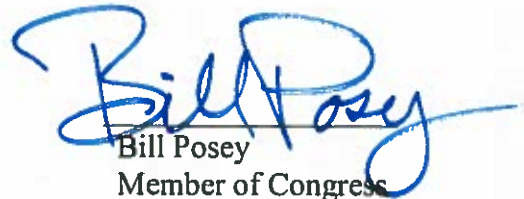
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¹²

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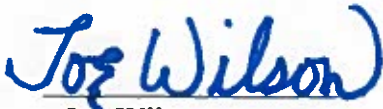
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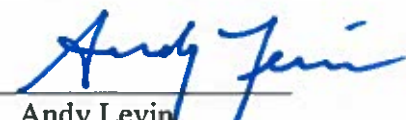
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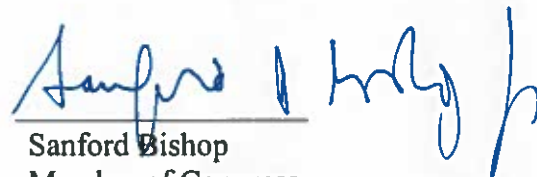
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