

**Congress of the United States**  
**Washington, DC 20515**

March 16, 2018

The Honorable Kay Granger  
Chairwoman  
Subcommittee on Defense  
House Appropriations Committee  
U.S. House of Representatives  
Washington, D.C. 20515

The Honorable Peter Visclosky  
Ranking Member  
Subcommittee on Defense  
House Appropriations Committee  
U.S. House of Representatives  
Washington, D.C. 20515

Dear Chairwoman Granger and Ranking Member Visclosky:

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 2019 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 2017, Congress appropriated an aggregate of \$71 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 2017, there was only enough research funding available to fund 18.6 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, and develop assays and animal models necessary for translating basic scientific discoveries into clinical treatments.

To date, patient organizations have invested more than \$20.3 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 TSCR in fiscal year 2019.


Sincerely,



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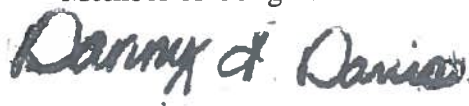
  
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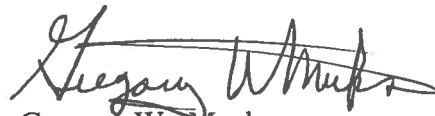
  
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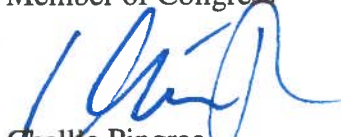
  
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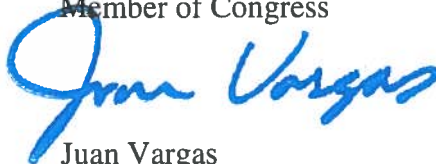
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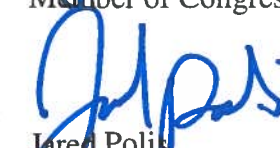
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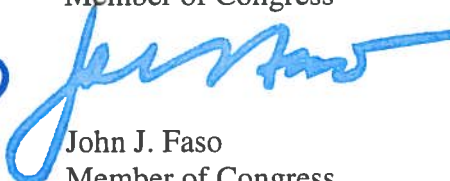
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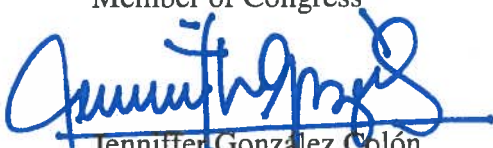
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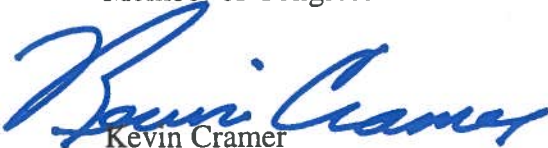
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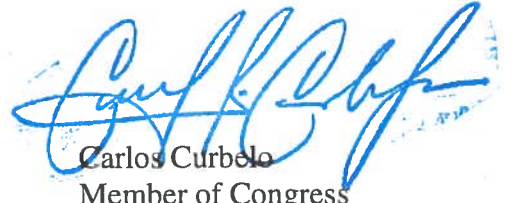




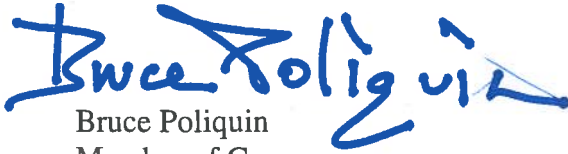
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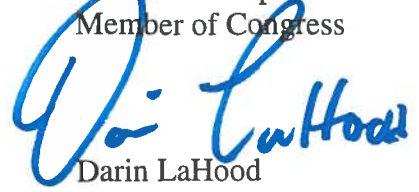
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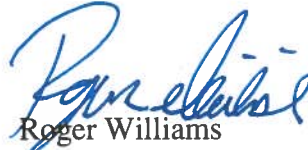
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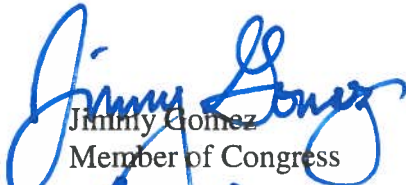
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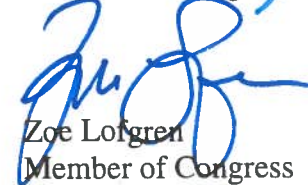
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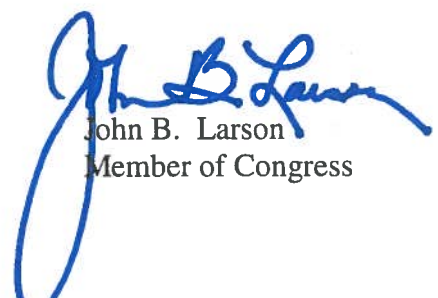
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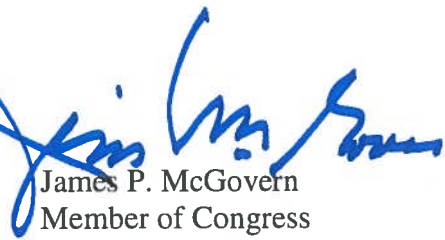
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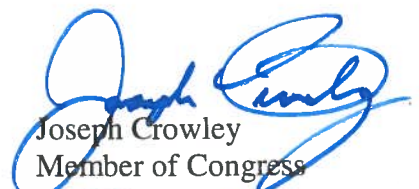




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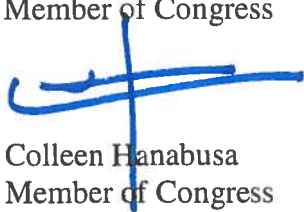
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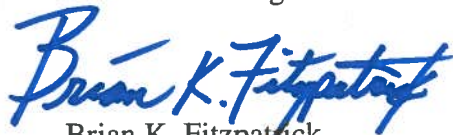
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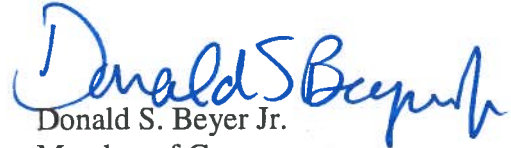
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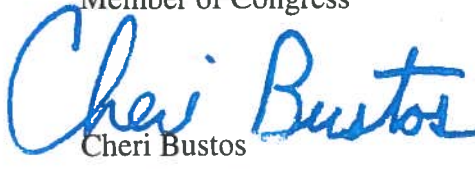
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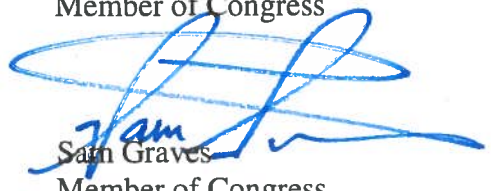
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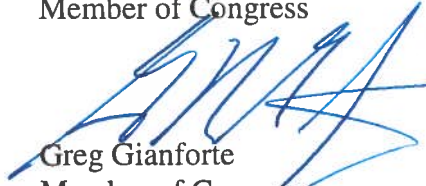
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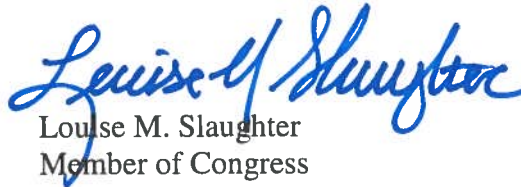
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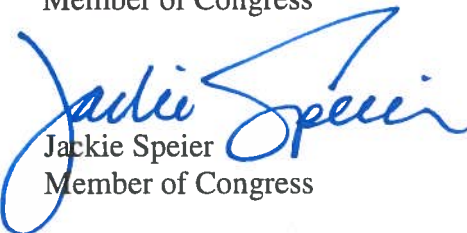
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