

Congress of the United States
Washington, DC 20515

March 29, 2023

The Honorable Ken Calvert
Chair
Subcommittee on Defense
Committee on Appropriations
H-405 Capitol Building
Washington, DC 20515

The Honorable Betty McCollum
Ranking Member
Subcommittee on Defense
Committee on Appropriations
1036 Longworth House Office Building
Washington, DC 20515

Dear Chairman Calvert and Ranking Member McCollum:

As you begin to craft the Fiscal Year (FY) 2024 Department of Defense (DoD) Appropriations bill, we respectfully request that you include \$10 million in FY 2024 funding for the Tuberous Sclerosis Complex Research Program (TSCRCP) 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 furthering our understanding of traumatic brain injury and other medical conditions like cancer and diabetes, and research at the TSCRCP is critical to ongoing progress.

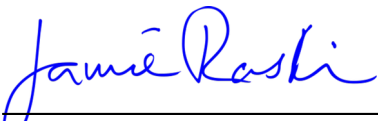
From FY 2002 to FY 2023, Congress appropriated an aggregate of \$113 million to the TSCRCP. This well-established program, which has enjoyed bipartisan support from Congress, awards grants competitively to cutting edge research proposals aimed at gaining a better understanding of this complex disorder. Research at the TSCRCP 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 TSC Alliance, representing the patient community.

While this research has led to significant breakthroughs, far more is needed if we hope to find more effective treatments for those who suffer with TSC and ultimately a cure. In Fiscal Year 2022 (the most recent year for which data is available), only 20% of research applications were funded by the TSCRCP, and 12 applications that scored in the outstanding or excellent range (totaling \$6.5 million) were not funded. 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, advance 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.

To date, patient organizations have invested more than \$34 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 build on these private sector commitments, and we urge you to appropriate \$10 million in necessary funding to continue the TSCR in FY2024. We are extremely grateful for the support your subcommittee has provided over the years for the TSCR.

Sincerely,



Jamie Raskin
Member of Congress



Brian Fitzpatrick
Member of Congress



Gregorio Kilili Camacho
Sablan
Member of Congress



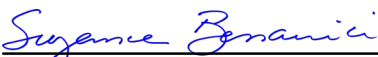
Vicente Gonzalez
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Teresa Leger Fernández
Member of Congress



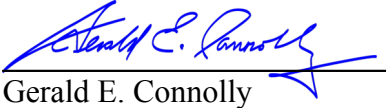
Brian Higgins
Member of Congress



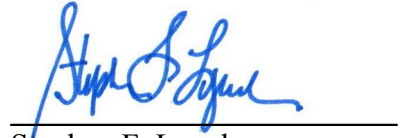
Suzanne Bonamici
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Gerald E. Connolly
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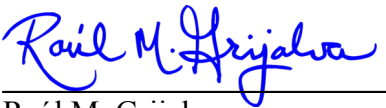
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Mark DeSaulnier
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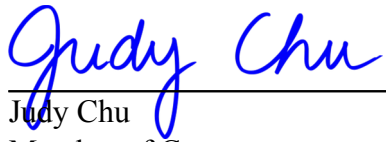
Jason Crow
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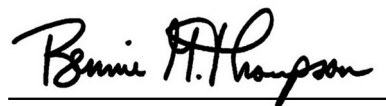
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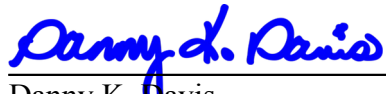
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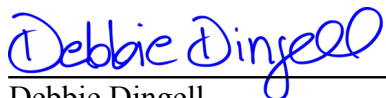
Nicole Malliotakis
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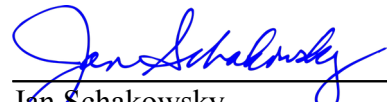
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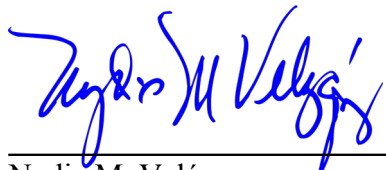
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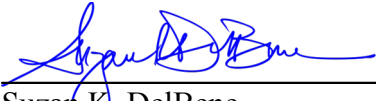
Mikie Sherrill
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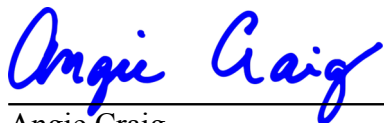
Bill Foster
Member of Congress



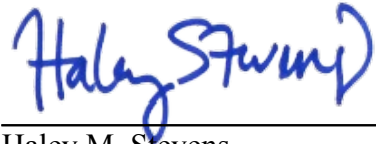
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Veronica Escobar
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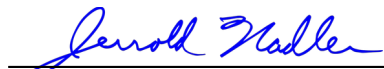
Rashida Tlaib
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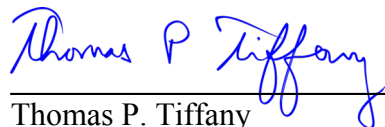
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Emanuel Cleaver, II

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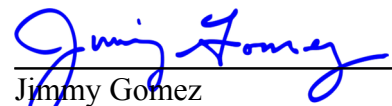
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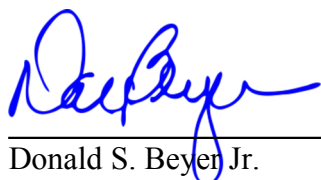
Earl Blumenauer
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Marc A. Veasey
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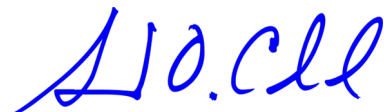
Glenn Grothman
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Donald S. Beyer Jr.
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Sam Graves
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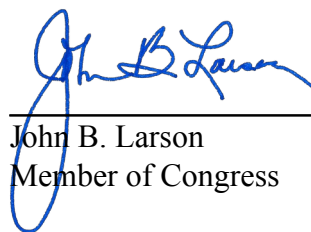
Salud Carbajal
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Lisa Blunt Rochester
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Katie Porter
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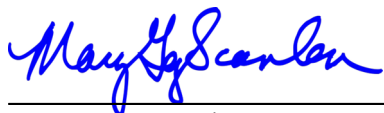
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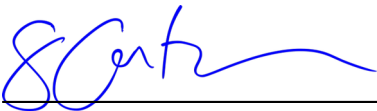
Shontel M. Brown
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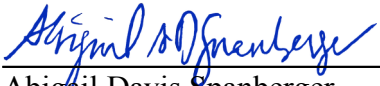
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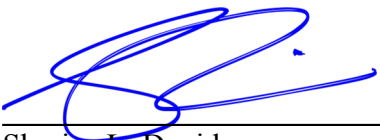
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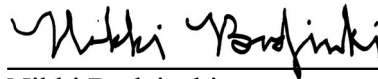
Pete Stauber
Member of Congress



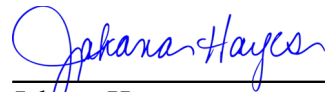
Ayanna Pressley
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Nikki Budzinski
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Andrew R. Garbarino
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Al Green
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Darin LaHood
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Bill Pascrell, Jr.
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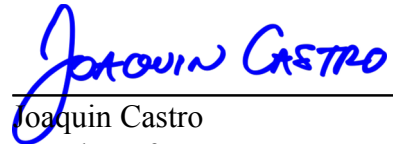
Cori Bush
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Raul Ruiz, M.D.
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Yvette D. Clarke
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Frank D. Lucas
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Aaron Bean
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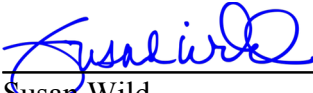
Chris Deluzio
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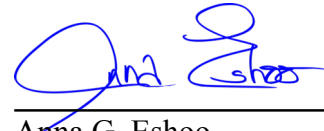
Troy Carter
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Raja Krishnamoorthi
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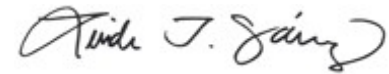
Susan Wild
Member of Congress



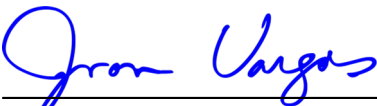
Anna G. Eshoo
Member of Congress



Mike Kelly
Member of Congress



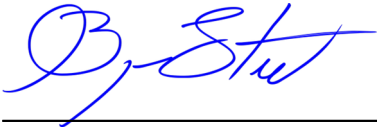
Linda T. Sánchez
Member of Congress



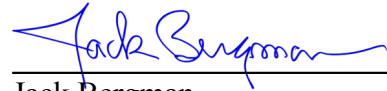
Juan Vargas
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Jeff Duncan
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Bryan Steil
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Jack Bergman
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Nick LaLota
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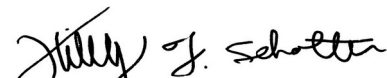
Jamaal Bowman, Ed.D.
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Julia Brownley
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Lucy McBath
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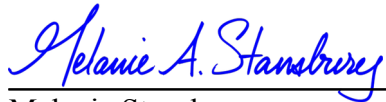
Eric Sorensen
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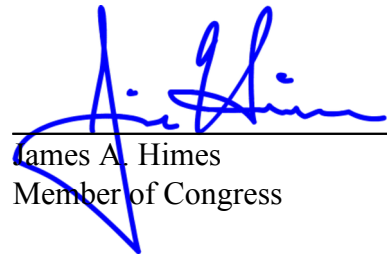
Melanie Stansbury
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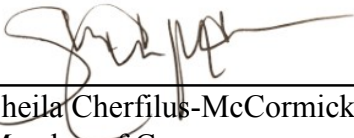
Darren Soto
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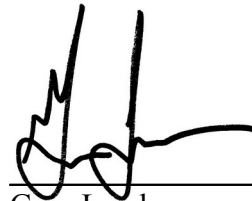
Sheila Cherfilus-McCormick
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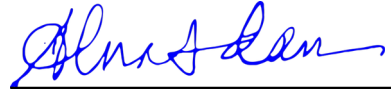
Randy Feenstra
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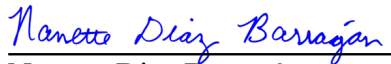
Marcus J. Molinaro
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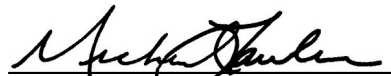
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María Elvira Salazar
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Eleanor Holmes Norton
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Greg Stanton

Greg Stanton
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Bruce Westerman

Bruce Westerman
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Barry Moore

Barry Moore
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