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 affects 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 TSCRP in fiscal year 2019.

Sincerely,

Ileana Ros-Lehtinen  
Member of Congress

Dave Loebsack  
Member of Congress
Doris Matsui
Member of Congress

Joe Courtney
Member of Congress

Frank Lucas
Member of Congress

Tim Walz
Member of Congress

William R. Keating
Member of Congress

Luis V. Gutiérrez
Member of Congress

Don Young
Member of Congress

Leonard Lance
Member of Congress

Gregorio Kilili Camacho Sablan
Member of Congress

Linda T. Sánchez
Member of Congress

Alcee L. Hastings
Member of Congress

Rosa L. DeLauro
Member of Congress

Blake Farenthold
Member of Congress

Richard M. Nolan
Member of Congress

C.A. Dutch Ruppersberger
Member of Congress

Walter B. Jones
Member of Congress

Jan Schakowsky
Member of Congress

Rick Crawford
Member of Congress

Emanuel Cleaver, H
Member of Congress

Bill Pascrell, Jr.
Member of Congress

Judy Chu
Member of Congress

Adolfo Sires
Member of Congress

Adam B. Schiff
Member of Congress

Frank A. LoBiondo
Member of Congress

Daniel Lipinski
Member of Congress

Christopher H. Smith
Member of Congress

Wm. Lacy Clay
Member of Congress

Al Green
Member of Congress

Steve Cohen
Member of Congress

Duncan Hunter
Member of Congress
Ron Kind
Member of Congress

Mark Takano
Member of Congress

Kathleen M. Rice
Member of Congress

Tony Cárdenas
Member of Congress

Raúl M. Grijalva
Member of Congress

Lee Zeldin
Member of Congress

Marc A. Veasey
Member of Congress

Lynn Jenkins
Member of Congress

Jennifer González-Colón
Member of Congress

Carol Shea-Porter
Member of Congress

Donald Norcross
Member of Congress

Bonnie Watson Coleman
Member of Congress

Juan Vargas
Member of Congress

Grace F. Napolitano
Member of Congress

John J. Faso
Member of Congress

John Katko
Member of Congress

Adriano Espaillat
Member of Congress

John K. Delaney
Member of Congress

Niki Tsongas
Member of Congress

Kevin Cramer
Member of Congress

Trent Kelly
Member of Congress

Dave Trott
Member of Congress

Kyrsten Sinema
Member of Congress

Jared Polis
Member of Congress

Rodney Davis
Member of Congress

Robert A. Brady
Member of Congress

Kathy Castor
Member of Congress

Yvette D. Clarke
Member of Congress

James R. Langevin
Member of Congress

G. K. Butterfield
Member of Congress
Kurt Schrader  
Member of Congress

John Garamendi  
Member of Congress

Bill Flores  
Member of Congress

Suzan K. DelBene  
Member of Congress

Frederica S. Wilson  
Member of Congress

Ted Deutch  
Member of Congress

F. James Sensenbrenner  
Member of Congress

Eliot L. Engel  
Member of Congress

Paul Tonko  
Member of Congress

Jackie Speier  
Member of Congress

Diana DeGette  
Member of Congress

Thomas MacArthur  
Member of Congress

Vicky Hartzler  
Member of Congress

Ed Perlmutter  
Member of Congress

Greg Gianforte  
Member of Congress

Bennie G. Thompson  
Member of Congress

Eddie Bernice Johnson  
Member of Congress

Louise M. Slaughter  
Member of Congress