United States Senate

WASHINGTON, DC 20510

Wednesday, March 16, 2016

Senator Thad Cochran
Chairman
Subcommittee on Defense
Committee on Appropriations
122 Senate Dirksen Building
Washington, DC 20510

Senator Richard Durbin
Ranking Member
Subcommittee on Defense
Committee on Appropriations
113 Senate Dirksen Building
Washington, DC 20510

Senator Roy Blunt
Chairman
Subcommittee on Labor-Health and
Human Services-Education
131 Senate Dirksen Building
Washington, DC 20510

Senator Patty Murray
Ranking Member
Subcommittee on Labor-Health and
Human Services-Education
156 Senate Dirksen Building
Washington, DC 20510

Dear Chairmen and Ranking Members:

We are writing to encourage continued funding for Tuberous Sclerosis Complex (TSC) research for Fiscal Year 2017, through the Tuberous Sclerosis Complex Research Program (TSCRP) and existing research initiatives at the National Institutes of Health (NIH).

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 has proven to have a significant impact on our understanding of traumatic brain injury and other medical conditions like cancer and diabetes, and we believe that the TSCRP is critical to ongoing progress.

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. Coordination between NIH and the Department of Defense (DoD) is managed by a trans-NIH working group, led by the National Institutes of Neurological Disorders and Strokes, with participation from eight separate Institutes, DoD, and the Tuberous Sclerosis Alliance. This working group has achieved exemplary results with breakthroughs in TSC research leading to two FDA-approved indications for a drug that shrinks brain and kidney tumors associated with TSC.

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 from TSC and to prevent its occurrence in future generations. Continued funding is critical to support clinical studies to validate biomarkers and outcome measurements necessary to accelerate development of new therapeutic agents and to understand the biology underlying the wide variation in

severity of manifestations among individuals with TSC. Furthermore, this investment is necessary to, attract new researchers into this field of study and to develop assays and animal models necessary for translating basic scientific discoveries into clinical treatments.

Ongoing support is necessary to move this research closer to ultimately finding a cure for tuberous sclerosis complex, and we urge you to appropriate the continued funding necessary to advance the TSCRP in Fiscal Year 2017.

Sincerely,

Johnny Isakson
U.S. Senator

Christopher S. Murphy
U.S. Senator

Edward J. Markey
U.S. Senator

Cory A. Booker
U.S. Senator

Charles Grassley
U.S. Senator

Martin Heinrich
U.S. Senator

Jeff Merkley
U.S. Senator

Elizabeth Warren
U.S. Senator

Charles E. Schumer
U.S. Senator

Mazie K. Hirono
U.S. Senator

Jeanne Shaheen
U.S. Senator

Benjamin L. Cardin
U.S. Senator

Robert Menendez
U.S. Senator

Tammy Baldwin
U.S. Senator

Jack Reed
U.S. Senator

Gary C. Peters
U.S. Senator

Sheldon Whitehouse
U.S. Senator

Daniel Sullivan
U.S. Senator

Richard Blumenthal
U.S. Senator

Sherrod Brown
U.S. Senator

Debbie Stabenow
U.S. Senator

Christopher A. Coons
U.S. Senator

Kirsten Gillibrand
U.S. Senator

Dianne Feinstein
U.S. Senator

Ron Wyden
U.S. Senator