

# United States Senate

WASHINGTON, DC 20510

March 26, 2015

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  
115 Senate Dirksen Building  
Washington, DC 20510

Senator Roy Blunt  
Chairman  
Subcommittee on Labor-Health and  
Human Services-Education  
135 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

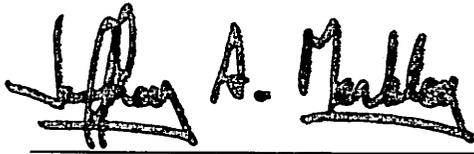
Dear Chairmen and Ranking Member:

We are writing to support a continuation of funding for Tuberous Sclerosis Complex (TSC) research in the fiscal year 2016 appropriations process, through the Tuberous Sclerosis Complex Research Program (TSCRP) and existing research initiatives at the National Institutes of Health (NIH).

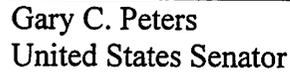
Tuberous sclerosis complex (TSC) is a genetic condition that afflicts an estimated 50,000 Americans, causing tumors in the kidneys, lungs, liver, heart, eyes, skin, and brain. Researchers have linked TSC to seizures, autism spectrum disorder and severe intellectual disability. Research on TSC is also 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 2015, Congress appropriated an aggregate of \$59 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. 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, representing patient organizations. 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 with TSC and prevent its occurrence in future generations. In fiscal year 2014, there was only enough research funding available to fund 18 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



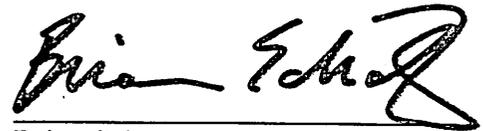
Jeff Merkley  
United States Senator



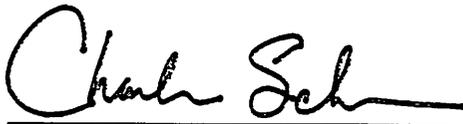
Gary C. Peters  
United States Senator



Jack Reed  
United States Senator



Brian Schatz  
United States Senator



Charles E. Schumer  
United States Senator



Jeanne Shaheen  
United States Senator



Debbie Stabenow  
United States Senator



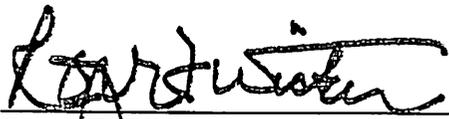
Dan Sullivan  
United States Senator



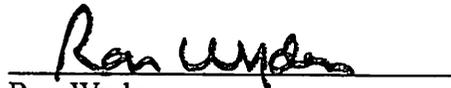
Elizabeth Warren  
United States Senator



Sheldon Whitehouse  
United States Senator



Roger F. Wicker  
United States Senator

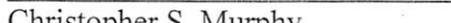


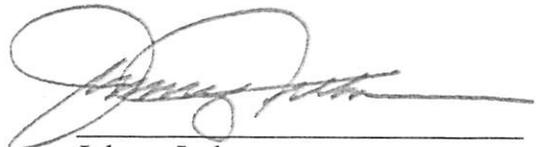
Ron Wyden  
United States Senator

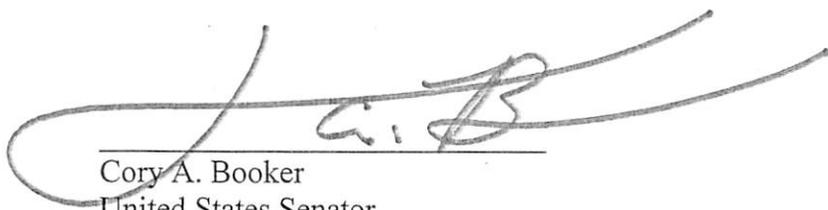
this field of study, and develop assays and animal models necessary for translating basic scientific discoveries into clinical treatments.

To date, patient organizations have invested more than \$18 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 2016.

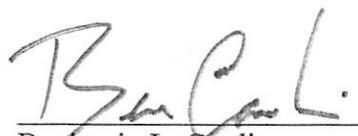
Sincerely,

  
Christopher S. Murphy  
United States Senator

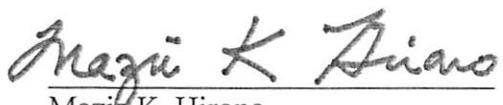
  
Johnny Isakson  
United States Senator

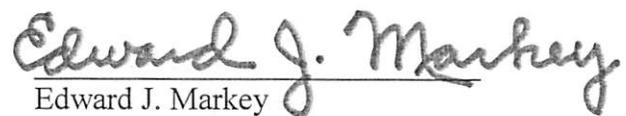
  
Cory A. Booker  
United States Senator

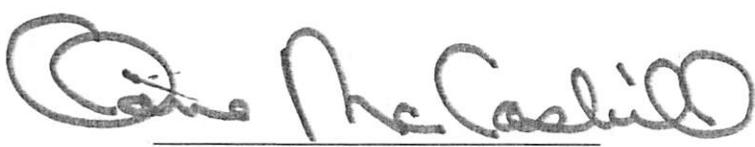
  
Sherrod Brown  
United States Senator

  
Benjamin L. Cardin  
United States Senator

  
Kirsten E. Gillibrand  
United States Senator

  
Mazie K. Hirono  
United States Senator

  
Edward J. Markey  
United States Senator

  
Claire McCaskill  
United States Senator

  
Robert Menendez  
United States Senator