

Government Relations Overview

The TSC Alliance contracts with the Washington, D.C.-based firm, Cavarocchi, Ruscio, Dennis Associates, L.L.C. (CRD Associates), for assistance with its government relations programs.

Senior VP Mark Vieth works closely with our Board, staff, and grassroots volunteers to advance TSC research programs within the federal government by assisting with strategic planning, message development, initiating key contacts, and providing counsel about the inner workings of the legislative process.

The TSC Alliance is one of several non-profit health organizations represented by CRD Associates including the Alzheimer's Association, the Cooley's Anemia Foundation, and the Modell Foundation. The TSC Alliance is a member of the Defense Health Research Consortium (DHRC), which is coordinated by Mark Vieth.

State Initiatives

Our government relations efforts focus on increasing federal and state appropriations for TSC research, raising awareness, and collaborating with government partners to drive TSC research forward and improve clinical care and treatment options for individuals with TSC. Currently we have state initiatives in Missouri, Maryland, and Alabama.

The Maryland state budget included continued appropriations of \$500,000 for the TSC Center of Maryland in 2023. Since FY20, the State of Maryland has appropriated \$2.85 million to support the TSC Center of Maryland. Directed by Peter Crino, MD, PhD, Chair, Department of Neurology, University of Maryland School of Medicine, the TSC Center of Maryland integrates world-class clinical care with research, education, and outreach. The TSC Center of Maryland provides clinical evaluation, care, and treatment in collaboration with the Clinical Center for Adults with Neuro-Developmental Disabilities (CCAND) for adults with autism, intellectual disability, and epilepsy. The TSC Center of Maryland also provides Maryland residents access to internationally recognized experts in adult TSC care. Through this collaborative partnership between private, nonprofit, and governmental agencies, Maryland is now recognized as a premier center for adult care and research in TSC.

The Missouri State Legislature appropriated \$500,000 In the state's 2023 budget for the TSC Centers of Missouri, including Washington University in St. Louis and Mercy Hospital in Kansas City. Since 2015, the State of Missouri has appropriated \$3 million to support these important initiatives with \$1.875 million released to move scientific advances forward. The Washington University Tuberous Sclerosis Clinic is committed to a three-fold mission of basic science research, clinical patient research, and care for TSC patients. Directed by Michael Wong, MD, PhD, Professor of Neurology, Pediatrics, and Neurobiology, Washington University School of Medicine, the Washington University Tuberous Sclerosis Clinic implements important new initiatives, including expansion clinical care from childhood into adulthood, innovative clinical drug trials, and a laboratory drug screening program for TSC. This funding also supports the TSC Clinic at Mercy Hospital in Kansas City, directed by Mohammed Ilyas, MD, to ensure access to TSC care throughout the state.

The Alabama State Legislature appropriated \$250,000 funding to support the University of Alabama at Birmingham (UAB) TSC Center of Excellence. Rep. Chris Pringle helped champion this state initiative. The UAB TSC Center of Excellence, located in Birmingham, was the first of its kind in the Southeast, serving patients with an established or suspected diagnosis of TSC. This funding will be

targeted to support the TSC Clinic infrastructure and the UAB TSC research program. The UAB TSC Clinic is a TSC Alliance Center of Excellence and is co-directed by Martina Bebin, MD, MPA, and Bruce Korf, MD, PhD.

Federal Initiatives

The TSC Alliance advocates for increased financial support of TSC initiatives through the following federal agencies:

- The National Institutes of Health (NIH)
 - Including National Center for Advancing Translational Science/Office of Rare Disease Research (NCATS/ORDR), National Institute on Neurological Disorders and Stroke (NINDS), National Cancer Institute (NCI), National Heart, Lung and Blood Institute (NHLBI), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), National Institute of Child Health and Human Development (NICHD), National Institute of Mental Health (NIMH), and National Human Genome Research Institute (NHGRI)
- The Tuberous Sclerosis Complex Research Program (TSCRCP) at the Congressionally Directed Medical Research Program (CDMRP) administered through the Department of Defense (DoD)
- Centers for Disease Control (CDC)
- National Center for Birth Defects and Developmental Disabilities (NCBDDD)
- Food and Drug Administration (FDA)
- Social Security Administration (SSA)
- Health Resources and Services Administration (HRSA)

The TSC Alliance also monitors legislative and policy issues that would impact the TSC community, such as healthcare reform and medication access issues, and works closely with other organizations, including, but not limited to The LAM Foundation, Epilepsy Foundation of America, the National Organization for Rare Diseases (NORD), Rare Disease Legislative Advocates (RDLA), EveryLife Foundation for Rare Diseases, Global Genes, Research!America, and American Thoracic Society Patient Advisory Roundtable (ATS PAR).

Tuberous Sclerosis Complex Research Program (TSCRCP)/March on Capitol Hill

Although our government relations efforts continue year-round, activity peaks in February/March when we encourage our grassroots supporters to join us in Washington, DC or to advocate with their elected officials virtually to educate their members of Congress about TSC and why increased federal funding for TSC research is critically needed.

Typically taking place in late February/early March, the annual TSC Alliance March on Capitol Hill is a grassroots program advocating for federal funding for the TSCRCP. Total cumulative funding for the TSCRCP has been \$113 million since 2002.

Our success in securing this vital funding can be attributed to our annual March on the Hill and ongoing advocacy by the TSC community. The FY24 Dear Colleague Letters were circulated by Representatives Jamie Raskin (D-MD) and Markwayne Mullin (R-OK) in the House and Senators Martin Heinrich (D-NM) and Kevin Cramer (R-ND) in the Senate. The House letter was signed by 217 Representatives and the Senate letter was signed by 41 Senators.

On September 29, 2023, the House approved its version of the fiscal year 2024 Defense Appropriations Act. During debate, the House approved by voice vote a bipartisan amendment

offered by Representatives Jamie Raskin (D-MD) and Brian Fitzpatrick (R-PA) to increase funding for the Tuberous Sclerosis Complex Research Program (TSCR) at the Department of Defense (DoD) from its current level of \$8 million to \$10 million.

Congress still needs to pass full spending bills for FY24 to fund the DoD, which is funded at existing levels until February 2, 2024.