**TSC Alliance**

**Government Relations Committee Meeting**

**October 13, 2023**

***DRAFT***

**ATTENDANCE**

**Committee Members (Voting):** Chip Burkhalter (Chair), Dana Holinka, Jessica Krefting, Sean Shillinger

**Committee Members (Non-Voting):**  Danielle Clark, Will Cooper, Sr.\*, Margaret Cox\*, Jean Leonard\*, John Richards, Lauren Shillinger\*

**Non-Committee Board Members (Non-Voting):** Derek Bauer, Matt Bolger, Peter Crino, Rob Grandia, Jonathan Goldstein, Bill Joseph, Darcy Krueger, Heather Lens, Laura Marks

**Other Guests (Non-Voting):** Frances Harper,Mark Vieth\*

**Staff:** Ayat Abi, Liz Cassidy, Zoë Fuchs\*, Jaye Isham, Carly Kaye\*, Shelly Meitzler, Ashley Pounders, Gail Saunders, Katie Smith

\* *Denotes connection via Zoom*

Chip Burkhalter confirmed a quorum and called the meeting to order at 3:36 pm ET.

**Discussion and Approval of Minutes from March 1, 2023 Government Relations Committee Meeting**

*Krefting* moved to approve the minutes from the March 1, 2023 Government Relations Committee Meeting. *Shillinger* seconded the motion. *The motion was approved without dissent.*

**Update on TSCRP Appropriations**

The House has brought their version of the Defense Bill to the floor. The TSCRP is in at $10 million. The Senate has not yet done their version of the bill. The government is operating under a continuing resolution (CR) through November 17. We are hopeful the additional $2 million will stay in the budget. In the event there is a long-term CR, the TSCRP would likely be funded at the existing level of $8 million and the $2 million increase would not happen. Additionally, there might be a 1% cut ($80k) to the program.

**2024 March on Capitol Hill**

The 2024 March on Capitol Hill is February 27-29. We are planning to hold a Congressional Briefing on Wednesday, February 28, and are working with Senator Eric Schmitt’s (R-MO) office on this. The March on Capitol Hill will consist of both virtual and in-person meetings again in 2024.

**Planning for NIH Report Language Sponsors in FY25**

Our NIH report language did not make it into the Senate’s version of the Labor, Health and Human Services bill. Senator Chris Murphy (D-CT) usually shepherds our language through the process. Next year we need to have language ready in early January along with a plan for who will submit it, which would ideally include a Democrat and a Republican in both the House and Senate. We will provide the language before the March on Capitol Hill but should consider how many asks we are giving an office. We could also consider targeting appropriators since they often do not sign the Dear Colleague Letter.

Report language has to vary from year to year, and for FY25, we want to ask for an update to the NIH strategic plan, which was last updated 2015.

Earlier this year, the following FY24 language was submitted:

**Tuberous Sclerosis Complex Report Language for inclusion in the FY24 Labor-HHS-Education Appropriations Act**

**Centers for Disease Control and Prevention (CDC)**

**National Center for Birth Defects and Developmental Disabilities**

*Tuberous Sclerosis Complex -* The Committee encourages CDC to take into consideration TSC as a possible cause of autism, epilepsy, and cardiac rhabdomyomas in its surveillance network. Because ongoing clinical trials are investigating the impact of preventative therapy in infancy to improve outcomes in epilepsy and autism in TSC, the Committee encourages CDC to counsel researchers and other stakeholders to facilitate development and pilot of a viable newborn screening assay for TSC.

**National Institutes of Health (NIH) Office of the Director**

*Tuberous Sclerosis Complex -* Because TSC impacts multiple organ systems, the Committee encourages the Director to coordinate the participation of multiple ICs to update the TSC research plan, last updated in 2015, aimed at addressing the numerous medical and neuropsychological burdens associated with TSC while deciphering the biology underlying phenotypic heterogeneity. Manifestations of TSC are highly variable among affected individuals, and TSC can be a model condition for developing precision medicine approaches to predict and treat each individual’s symptoms to maximize the benefit-risk ratio.

**State Funding Initiatives**

Margaret Cox gave an update on Alabama state funding. The TSC Clinic at the University of Alabama received $250,000 in supplemental funding. A day of advocacy for Alabama will likely take place in January as we need to ensure the funding stays in the budget.

In Maryland, the state funding is buried in the University of Maryland budget. Dr. Crino advised that we not draw attention to it.

In Missouri, we are planning for a day of advocacy in January. This year it did make a difference as the TSC Centers of Missouri were funded at $500,000 when our ask was for $350,000; it was funded at $250,000 last year.

For any state funding initiative, the TSC Clinic Director, institution, and advocacy community need to be involved and committed. Not all states are good candidates for a state funding initiative. In states with more than one TSC Clinic, the TSC Clinic Director needs to be engaged for us to advocate for funding for their clinic, or we can look at advocating for a competitive TSC grant program in the state. In Missouri, we have three recognized TSC Clinics, but not all the clinics participate in our advocacy initiatives and the one that doesn’t does not receive any of the state’s TSC funds.

There were additional TSC Global Awareness Day resolutions in California and Illinois in 2023.

To learn more about state advocacy, we have a state advocacy toolkit on TSC Academy at www.tscacademy.org.

**Review and Approve 2024 Government Relations Committee Goals**

1. Cultivate, educate and empower a premier constituent advocacy group to advance TSC initiatives at federal, state, and/or district levels.
   1. Develop and implement a strategy for both in-person and virtual March on Capitol Hill participants.
   2. Recruit and train lead government advocates in 30 states.
   3. Empower state coordinators to conduct additional follow up based on feedback forms from virtual or local March on Capitol Hill meetings.
   4. Work with Community Programs to engage underrepresented communities in the March on Capitol Hill in person and virtually and state days of advocacy, including conducting a baseline assessment by race and gender of our March on Capitol Hill advocates.
   5. Engage community volunteers in local advocacy in conjunction with Congressional recesses and Community Alliance events.
   6. Incorporate TSC Academy as part of the pre-March on Capitol Hill Training with 100% participation by new sponsored attendees.
2. Continue advocacy to maintain or increase Tuberous Sclerosis Complex Research Program (TSCRP) funding in the Department of Defense (DoD) budget. Further dialogue with Appropriations and Armed Services Committees to: 1) prevent damaging language in Authorizing bills, and 2) continue funding in the Appropriations bills.
   1. Continue developing relationships with House and Senate Dear Colleague Letter champions while maintaining level of co-signers obtained in FY24: House Letter led by Representatives Fitzpatrick (R-PA) and Raskin (D-MD) supported by 191 signers; Senate Letter led by Senators Cramer (R- ND) and Heinrich (D-NM) supported by 41 signers.
   2. Develop strategy to defend or secure $10 million for the TSCRP.
   3. In select districts, partner with The LAM Foundation to increase congressional outreach around federal funding in select districts.
   4. Participate in the Defense Health Research Consortium to protect DoD appropriations; engage researchers and universities in advocating in case of threats to funding.
3. Work with Congressional sponsor to submit report language incorporating TSC/TSC research in final HHS Bill.
4. Build and strengthen relationships to advocate for increased financial support of TSC initiatives from Department of Health and Human Services, including NIH, HRSA, PCORi, CDC, FDA and ARPA-H.
5. Explore expanded TSC advocacy initiatives to include opportunities to impact quality of life and access to research funding at state/regional/local levels.
   1. Remain vigilant about access to all health care (including expanded telehealth) and insurance programs, including Medicaid, and advocate for access to TSC treatments.
   2. Remain vigilant about medication access issues, including Patient Assistance Programs (PAPs), co-pays and insurance coverage.
   3. Maintain state funding in Maryland, Missouri and Alabama and selectively seize opportunities in other states should they arise.
6. Secure funding to support constituent training in advocacy and empowerment, including virtual advocacy.

There was an additional discussion around telehealth and state funding. The goals were not amended based on this discussion, but at the next committee meeting we can discuss telehealth advocacy following the wake of post-covid medical licensure expirations and assess whether or not a task force to address this is needed.

Mark Vieth provided this resource licensure across state lines: <https://telehealth.hhs.gov/licensure/licensing-across-state-lines#:~:text=A%20number%20of%20states%20have,already%20licensed%20in%20another%20state>.

*Holinka* motioned to approve the 2024 Government Relations Committee goals. *Shillinger* seconded the motion. The goals were approved.

**Next Meeting and Adjourn**

The next meeting will be scheduled for December.

There being no further business, *Krefting* moved to adjourn. *Holinka* seconded the motion. The meeting adjourned at 2:46pm ET.

Respectfully submitted,

Katie Smith

Director, Government and Global Affairs