**Tuberous Sclerosis Alliance**

**October 12, 2017 Government Relations Committee Meeting Minutes**

**October 12, 2017**

**DRAFT**

**In Attendance:**

**Committee Members (Voting):** Debora Moritz (Chair), Sara Chieffo, Bonnie Hogue Duffy, Julie Scroggins

**Committee Members (Non-Voting):** John Richards, Will Cooper (by phone)

**Board Members:** Tim Dills, James Achterhof, Laura Lubbers

**Incoming Board Members:** Tara Zimmerman, Rob Grandia, Dana Holinka

**Staff:** Katie Smith, Jaye Isham

**Guest:** Mark Vieth

Debora Moritz called the meeting to order at 7:40 pm.

**Approval of the Minutes from September 27, 2017**

A quorum of voting members was confirmed. *Duffy* moved and *Scroggins* seconded to approve the September 27, 2017 minutes. *The minutes were approved without dissent.*

**Review 2017 Committee Goals**

A discussion was held regarding the committee’s draft 2018 goals. It was suggested to add protect the TSCRP from damaging language through defense authorizations as part of an offensive strategy to reach new members of Congress to the goals. Moritz called for committee approval of the goals as amended. *Duffy* moved and *Scroggins* seconded. The goals were approved without dissent.

Goal 2 now reads “Continue advocacy to maintain 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.”

**NDAA Update**

Mark Vieth provided update on the National Defense Authorization Act (NDAA). Unfortunately the NDAA language approved by Senate will basically shut down medical research performed by the Department of Defense. 53 senators supported amendment to strike this language but weren’t allowed a vote. 54 Senators, including Republicans, signed a letter to support continued medical research. The House letter is currently being circulated. We hope to get a majority of members to sign this letter and get the issue resolved by early November. This may ultimately be resolved by the big four from the Armed Services Committee, Senators McCain (R-AZ) and Reed (D-RI) along with Representatives Thornberry (R-TX) and Smith (D-WA).

Mark mentioned dozens of “competing” Dear Colleague letters are also circulating but our letter is doing well.

Some Defense Health Research Consortium members have reduced grassroots outreach due to information overload.

Mark discussed process of conference committee. Once letter is done, must continue to work behind scenes to keep grassroots pressure going. Next year, we should focus efforts on asking Ranking Member, Senate Armed Services Committee, Senator Reed (D-RI) to fight for these programs at the committee level.

Tactics to use going forward were discussed, including reaching out to Brown University in Rhode Island, targeting grassroots advocates in Rhode Island to see if they can meet with Senator Reed’s local office, and ways to increase publicity through op eds, continued use of social media and #researchnotredtape. The Defense Health Research Consortium (DHRC) website was added to the TS Alliance website. Mark and DHRC members have also met with all members of the Armed Services Committee.

Sara Chieffo offered to make calls to TSCRP letter signers if needed for constituents who are burned out.

The Senate has not marked up their defense appropriations bill yet, but it will likely be completed by the end of the month. The House version has $6 million in for TSCRP. Committee chairs for appropriations support the CDMRP.

**ACA Update**

Recent Executive Orders by the President may destabilize the insurance market. An executive order signed October 12 could create two risk pools, like Republicans in Congress have been pushing.

**State Initiatives Update**

*Missouri*

Eric Schmitt became the State Treasurer of Missouri after having served as a State Senator and securing $1.5 million in appropriations for TSC research. In July, the Governor signed off on the FY18 state budget that included $250,000 in state funding for the TSC Center of Missouri, located at Washington University.

*Alabama*

The TS Alliance is working with former board chair Marion Adams, his wife Laura, Carole Pitard, and Dr. Martina Bebin, TSC Clinic Director at University of Alabama at Birmingham to identify possible opportunities for state funding to support TSC research in Alabama.

*Maryland*

Maryland Community Alliance Chair Lauren Schillinger and Frederica Struse, Chief of Staff for Senator Brian J. Feldman, have been working on a Maryland State Advocacy and Awareness Day for February 28, 2018 (Rare Disease Day).

TSC constituents will meet with local legislators and then hear a briefing from Dr. Peter Crino, Chair of Neurology Department at the University of Maryland. This is the first step toward advocating for TSC specific research funding in Maryland. Dr. Crino should find out if the University has done anything like this before.

*New York*

A funding request was submitted but may not go anywhere.

Would Colorado or Oklahoma be future opportunities? State funding has all been secured organically thus far

**Infantile Spasms (IS)Awareness Update**

IS Awareness Week (December 1—7) will culminate with a Congressional Briefing on Tuesday, December 5, including a breakfast briefing and panel discussion on IS. Rep. Blumenhauer (D-OR) reserved rooms and chairs the Neuroscience Committee. Infantile Spams Awareness Network (ISAN) drafted a congressional awareness resolution sponsored by Sens. Shelby (R-AL) and Brown (D-OH). The Senate should probably pass this.

**2018 March on Capitol Hill Update**

The next March on Capitol Hill will be held March 6-8, 2018. Dena Hook and April Cooper are assessing who will be invited to attend and funded by TS Alliance. More information to follow.

**Other Items**

John Richards discussed the San Diego National Conference model for getting people engaged in advocacy and suggested a focus on advocacy recruitment at the 2018 World TSC Conference.

Scroggins moved and Duffy seconded to adjourn the meeting. The motion carried without dissent. The meeting was adjourned at 8:57 pm.

Respectfully submitted,

Katie Smith, Manager, Research and Global Affairs