**Tuberous Sclerosis Alliance**

**Government Relations Committee Minutes**

**September 27, 2017**

**DRAFT**

**In Attendance:**

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

**Committee Members (Non-Voting):** Julie Blum, Will Cooper, Sr., Cathy Krinsky, John Richards

**Guests:** Mark Vieth

**Staff:** April Cooper, Jaye Isham, Kari Rosbeck, Katie Smith

Debora Moritz called the meeting to order at 3:01pm.

**Approval of the minutes from August 28, 2017**

A quorum of voting members was confirmed. *Scroggins* moved and *Gwinn* seconded to approve the August 28, 2017 minutes. *The minutes were approved without dissent.*

**Update to ACA**

Republicans do not have the number of votes they need to move the Graham-Cassidy legislation forward, the latest version of the attempt to repeal and replace the ACA. Healthcare may come up again at a later time, possibly during talks of a new budget resolution with tax reform.

**Update on NDAA**

Despite securing 53 cosponsors, the bipartisan Durbin-Blunt Amendment was not brought to a vote during the National Defense Authorization Act (NDAA) debate. The Senate’s approved version of the NDAA contains language stalling medical research programs at the Department of Defense (DOD). The House’s version does not contain any language that would be damaging to these programs. The NDAA will now go to a committee and be finalized by members of the House and Senate.

A bipartisan Dear Colleague Letter sponsored by Senators Richard Durbin (D-IL) and Roy Bunt (R-MO) is currently being circulated in the Senate. A House Dear Colleague Letter sponsored by Representatives Ryan Costello (R-PA), Peter King (R-NY), Sanford Bishop (D-GA) and Dave Loebsack (D-IA) should be finalized by the end of the week. The letters are in support of all medical research at the DOD and ask that any damaging language be removed from the final version that comes out of committee. Senator Roger Wicker (R-MS) sits on the Senate Armed Services Committee and has been in favor of medical research programs at the DOD in the past. Next year, we should see if Senator Jack Reed (D-RI) can fight damaging provisions at the authorizing committee level.

The Dear Colleague Letters will be circulated to the grassroots community and advocates will be asked to reach out to all their members of Congress. With the House letter, we will also circulate the roster for the Armed Services Committee. This falls under the Military Personnel Subcommittee. We should encourage advocates to email offices their personal stories. Any email should be made as personal as possible because form emails may not make it through emails filters. Mark Vieth will send a list Health and Defense staffers that can be circulated to March on Capitol Hill participants and Community Alliance Chairs. Advocacy efforts should be focused on getting the community to make personal asks to their members of Congress. We need to be mindful of advocacy burnout. Armed Services Committee members may not sign the Dear Colleague Letters and we hope to know who will be appointed to the conference committee in the next week. Mark will keep us updated on Dear Colleague Letter signers and the list of signers will be circulated to the community.

Mark is scheduling Defense Health Research Consortium (DHRC) meetings with key committee members in the House and Senate.

*Scroggins* moved and *Chieffo* seconded a motion to adjourn the meeting. There being no further business the meeting adjourned at 3:44 p.m.

Respectfully submitted,

Katie Smith, Manager, Research and Global Affairs