**TS Alliance Global Relations Committee**

**Meeting Minutes**

**March 2, 2017**

**Approved: October 13, 2017**

In attendance:

**Board Committee Members:** David Michaels (committee chair), Andrew Duffy (ex-officio), Debora Moritz

**Non-voting Committee Members:**  Matt Bolger, Darcy Krueger (by phone), Dan Bloom (by phone)

**Board Members:** Sara Chieffo, Jim Maginn

**Staff:** Calvin Ho, Jaye Isham, Katie Smith

Committee Chair David Michaels welcomed everyone and called the meeting to order at 11:06 am. A quorum of voting members was present was confirmed.

**Approval of Global Relations Committee Members for October 14, 2016**

There was a minor correction to change the approval of the minutes for October 14, 2016 title from Government Relations to Global Relations. *Moritz* moved and *Michaels* seconded to approve the October 14, 2016 minutes*. The minutes were approved without dissent.*

**Update on Global Partnerships**

*TS Alliance of Israel*

Dan Bloom gave an updated on the TS Alliance of Israel. The organization held two community meetings, continues to coordinate with TSC Clinics in Israel, and working to build on previous progress including its relationship with Novartis. In the past year, the organization welcomed Dr. John Bissler for a visit as well as Kari Luther Rosbeck and Katie Smith from the TS Alliance. The TS Alliance of Israel is currently preparing for its 2017 national meeting in November.

*TS Canada ST*

Andrew Duffy then gave an update on the Canadian organization. It has 6 board members and held a successful conference in Vancouver this past Fall. It also secured at $35,000 grant from Novartis and is working to find additional funding. Regarding care, Canada overall has continued challenges transitioning the care of children with TSC into care as adults and the organization hopes to learn more about care for adults with TSC in the United States. Duffy estimates they currently serve about 1,000 families and individuals with TSC currently.

*TS Alliance of Mexico and TS Alliance of ASEAN*

Katie Smith reported both these new organizations are in the process of becoming legal entities after signing formal agreements with the TS Alliance. The TS Alliance provided seed funding for both organizations. ASEAN is having difficulties with a name and is proceeding with a new application, which may take up to one year to complete. Mexico holds its patient meeting on May 15 and will continue to fundraise with its annual walk/run.

**Global Alliance Prospects**

Katie Smith and Darcy Krueger gave updates on a possible new Global Alliance in Hungary.

**Tuberous Sclerosis Complex International (TSCi) Update**

Katie Smith reported TSCi will be a co-host for the 2018 World TSC Conference and will provide guidance on programming and speakers to ensure the event appeals to people outside the United States.

**Other Business**

David Michaels and Katie Smith discussed next steps for writing a Global Relations Business Plan for the TS Alliance. Smith will provide a first draft for the committee to review in June with the goal to produce a final product for the October 2017 board meeting.

There being no further business, the meeting adjourned at 11:59 am.

Respectfully submitted,

Katie Smith