**Tuberous Sclerosis Alliance**

**Science and Medical Committee Minutes**

**Embassy Suites DC Convention Center and via Teleconference**

**March 2, 2017**

**Approved: June 28, 2017**

**In Attendance:**

**Committee Members (Voting):** Rebecca Anhang-Price, Martina Bebin (Co-chair), John Bissler, Laura Lubbers, Brendan Manning (Co-chair; by teleconference), Debora Moritz, Julie Scroggins

**Board Members:** Sara Chieffo, Andrew Duffy (ex officio), David Fitzmaurice, Tom Gwinn, Jim Maginn, David Michaels

**Guests:** Darcy Krueger (by teleconference), Lauren Shillinger, Sean Shillinger, Michael Wong

**Staff:** Calvin Ho,Jo Anne Nakagawa,Steve Roberds, Kari Rosbeck, Katie Smith

**Call to Order**

*Bebin* called the meeting to order at 10:03 a.m. and confirmed a quorum of voting members.

**Approval of minutes from January 11, 2017, committee meeting**

*Moritz* moved and *Lubbers* seconded to approve the minutes of January 11, 2017. *The minutes were approved without dissent.*

**New TSC Clinic Directors**

*Manning* moved and *Moritz* seconded to approve Charuta Joshi and Anna Jeong as new TSC Clinic Directors. *The motion carried without dissent.*

**New PAB member**

*Scroggins* moved and *Moritz* seconded to approve Charuta Joshi as a new member of the PAB. *The motion carried without dissent.*

**New TSC Clinic Committee Members**

*Moritz* moved and *Scroggins* seconded to approve Ashley Pounders and Tricia Bodnar as new TSC Clinic Committee Members. *The motion carried without dissent.*

**TSC Clinic Applications**

Steve stated that 15 new institutions were interested in becoming a registered TSC clinic. Currently, there are 48 clinics in US and 3 in Israel. Of the new applications, all 15 are in the US. Two are in Ohio, with one being down the road from the existing TSC Clinic at Cleveland Clinic.

Darcy noted there is a lot to be lost if we discourage interest in treating TSC, and a decision to stop accepting new TSC Clinics could appear exclusionary. He also pointed out that having a TSC Clinic can now help a hospital’s ranking in US News and World Report, which may be driving interest up. The committee discussed several valid reasons for having redundancy of clinics, even near one another, including insurance issues and the need for transition and adult care. Kari and Darcy both noted that community members could become angry at TS Alliance because the level and type of care experienced at different TSC Clinics listed on the website can be very different.

Martina suggested that we show more clearly on the website what different clinics can provide. Steve brought up that we have core standards and gold standards for clinics, and that this is a good opportunity to revisit what they are.

Julie brought up the possibility of becoming an accrediting body for TSC clinics. Darcy noted that it can be very complicated for an advocacy organization to get involved in accreditation, and that some hospitals are not allowed to self-report on the types of questions that accreditors would ask. However, patients would be free to self-report on their experiences with the care at those clinics. Rebecca volunteered to create patient experience survey on coordination of care at clinics.

Steve suggested that we make the distribution of and participation in a patient experience survey a requirement for all sites, and that we set up a Clinic Director mentoring requirement. Before their application gets approved, new TSC Clinic Directors would be required to communicate with an experienced TSC Clinic Director about the experience. Darcy suggested that clinics be required to participate in the TSC research community, e.g., through participation in scientific meetings every few years or referring clinical study participants.

**Patient-Focused Drug Development**

Steve mentioned that we had hired attorney and former FDA employee James Valentine to facilitate the PFDD meeting in June. Janet Woodcock and Jonathan Goldsmith are confirmed FDA speakers. The tangible deliverable from this meeting is the Voice of the Patient report, which TS Alliance will compile and FDA will use in its decision-masking going forward.

**Research Grant Program Schedule and LOI Plan**

The research grant program schedule is available on the website. We will follow up with the LOI review plan as the date gets closer.

**Updates on Requests for Travel Support for PREVeNT Trial Participants**

Martina explained that many families with infants participating in the PREVeNT trial are flying or driving more than 6 hours to the sites. The families are spending about $300-400 per visit for a one-night stay. Her goal is to make this trial accessible to any family with an infant with TSC, so she is looking for travel funding.

So far, she has received a $10,000 gift form the Pediatric Epilepsy Research Foundation. Julie confirmed that Bcureful’s board has voted unanimously to provide travel funding, as well. Steve said that TS Alliance will keep this need in mind for next year’s budget, in case we need to pitch in.

*Anhang Price* moved and *Moritz* seconded to adjourn the meeting. *The motion carried without dissent*. The meeting was adjourned at 10:58am.

Respectfully submitted,

Steve Roberds, Chief Scientific Officer