**Tuberous Sclerosis Alliance**

**Board of Directors Meeting Minutes**

**March 2, 2017**

**Approved: June 7, 2017**

**In attendance:**

**Voting Board Members:** Tim Dills (Chair), Beth Dean, David Fitzmaurice, Jim Maginn, Rebecca Anhang Price, Margaret Cox, David Michaels, Brendan Manning (by phone), Bonnie Hogue Duffy, Sara Chieffo, Julie Scroggins, Debora Moritz, Cassandra Carroll, Tom Gwinn

**Ex-Officio Board Member:** Andrew Duffy

**Endowment Fund Board:** Doug Loftus (Chair)

**Staff:** Kari Rosbeck, Rich Gollub, Steve Roberds, April Cooper, Jo Anne Nakagawa, Lisa Moss, Katie Smith, Christen Bell, Calvin Ho, Tye Hoffman, Jaye Isham, Dena Hook, Dan Klein, Rupal Desai, Gail Saunders, Shailee Upadhyay

**Community Members and Guests:** David Coit, Craig Elias, Gene Gilder, Kathi Dills, Cathy Krinsky, Lauren Shillinger, Sean Shillinger

**Corporate Advisory Board:** John Richards

**Call to Order & Convene the Board of Directors Meeting Tim Dills, Chair,**

**Board of Directors**

Tim Dills called the meeting to order at 5:03 pm and confirmed a quorum of board members.

**Chair’s Opening Comments, Tim Dills, Chair**

Tim noted what a successful set of meetings had occurred during the March on the Hill, that Sound Bites was a beautiful, successful event, raising ~$107,000, that the committee meetings were productive, and that the lunchtime speakers were excellent.

**Approval of the Minutes from the December 7, 2016 Meeting, Rebecca Anhang Price, Secretary**

A motion was made to approve the December 7 Board meeting minutes as written (*Moritz/Michaels*). *The minutes were approved without dissent.*

**Chief Executive Officer’s Report Kari Luther Rosbeck, President and CEO**

Kari Rosbeck provided updates in each of the TS Alliances four strategic domains.

**Accelerate Research**

* Three new industry partners joined the Preclinical Consortium in 2016: GW, UCB, PIQUR.
* Seven sites running PREVeNT trial launched December 1, and TS Alliance provided support for a TSCure coordinator to develop protocol and help apply for funding, which would add additional sites to Clinical Research Consortium.
* National history database achieved 2,071 enrollees, 176 blood samples (slightly shy of goal of 200); goal for this year is 600, of which there will be a subset of tissue samples. The team is trying to connect the biosample repository with natural history database.
* Goal in the grants program was to fund 6 grants at least $450,000 per year; in 2016, well-exceeded this goal with over $900,000 in grants funded.

**Support and Empower Constituents**

* 9,804 constituents added to our database since 2014 through pop-ups on the website and participation in events through Luminate.
* 52 TSC Clinics (49 in the US and 3 in Israel) providing comprehensive care.
* 27 national/international professional meetings were attended or sessions led by staff in 2016, well exceeding the goal of attending 15 such meetings.
* 2,344 educational trainings for parents were posted and shared with our constituents last year – 118% increase over 2013.
* 65 school meetings were attended by the Vice President of Outreach – 150% increase over 2013.
* 1,515 individuals/families reached by a Clinic Ambassador – 536% increase over 2013.
* 72 new volunteer leaders were recruited totaling 173 since we launched the strategic plan in 2014.
* 3 new Global Alliance/Partners were added in 2016 including TS Canada ST, TS Alliance of Mexico, TS Alliance of ASEAN Foundation.
* A higher goal for website traffic has been set for 2017, which the team feels confident can be achieved given the launch of the new website, and that the site is already more 30% ahead of target as of the end of February 2017.

**Mobilize to Increase Investments**

* Achieved over 80 million media impressions over the course of 2016, a sharp increase over the prior years.
* Unlock the Cure: ACT Now! Raised raised $3,628,673 in 2016 and $4,293,818 overall.
* Endowment contributions have increased from $197,200 in 2013 to $206,000 in 2016 (though a decision was made to defer the contribution to future years). The goal is $250,000 in annual contributions by 2018.

**Build and Strengthen Organization**

* The goal from the strategic plan is to achieve at minimum 3% annual increase in program expenses with balanced budget; 80/20 program/expense ratio with revenue of $5.5 million by 2018 while obtaining 4 star Charity Navigator rating
  + In 2016, there was 32% Program Growth
  + $5,240,880 revenue; $4,924,614 expenses
* 76.26% program/23.74% admin and fundraising, resulting in a 3-Star Charity Navigator Rating; TS Alliance maintained the Better Businesss Bureau Wise Giving Program Recognition, Platinum Level Guidestar Charity distinction
* 4 new Board members were recruited to the board for 2017 with an expertise in government affairs, accounting, executive hospitality procurement and nonprofit.
* Staff retention held steady at 81.25%.
* Staff developed Emergency Back Up Plan for every department and every position, short- and long- term.
* Hired new Director of Special Events and Corporate Partnerships and Science Project Coordinator and retained a National Walks Coordinator on contract to strengthen depth of staffing and services.

Kari also noted that:

* The Preclinical Consortium is playing a role in impacting drug development with funding focused on collaboration. The Consortium provides the opportunity to build relationships with industry much earlier in the pipeline.
* The Alliance is working to grow the President’s Council with an upcoming event hosted by Julianne Moore.
* There are several upcoming conferences, meetings, walks, and workshops upcoming in 2017. In addition, Comedy for a Cure, a signature national fundraising event, is slated for Sunday, April 2, 2017.

She noted that board members can help to further support the Alliance by:

* Recruiting future board members with ability to raise substantial major gifts.
* Identifying and cultivating a new donor, especially one who might join the President’s Council.
* Identifying sponsors for 2018 World TSC Conference
* Crowdfunding sponsorships.
* Participating in event committees and local community events.

**Treasurer’s Report Jim Maginn, Treasurer**

Jim Maginn presented an overview of 2016 financial performance for the TS Alliance, as follows:

Revenues

Special Events - $148k under budget

* Walks came in $91k under.
* Major events (Comedy for a Cure and Minnesota SoundBites) came in $42k under.

Major Donors - $321 under budget

* The $250k budgeted for Gregg Engles came in as a $1.5m grant, and is reflected in the Grants line item.
* Bill Watts was budgeted at $150k but came in $98 higher than that.
* There was $50k budgeted for Board Development gifts which did not materialize.
* There was $50k budgeted for the Dinsdales, that would have come at year end, but we did not pursue in 2016, hoping to bring that in during 2017.

Grants - $1.35m over budget

* The Engles Family Foundation’s $1.5m grant was originally budgeted as a $250k gift in the major donor category.
* The Lundbeck Impact Fund grant exceeded budget by $163k this year.
* We did not receive the $200k PERF grant that was budgeted.

Contribution from the Endowment - $206k under budget

* Not needed this year, better to save it for use in future years.

Expenses

Travel - $81k over budget

* Biggest travel costs were for the March on the Hill and Community Alliance activities - $76k, Global Outreach - $48k, and Development - $41k.
* The main ones creating the over-budget variance were: March on the Hill /Community Alliance activities $28k, Development - $26k, and Research - $13k.

Training Conferences and Exhibits - $40k over budget

* The biggest costs were for the March on the Hill/Community Alliance activities - $60k and Professional Education (includes American Epilepsy Society Meetings) - $25k.
* The main ones creating the over-budget variance were – the March on the Hill/Community Alliance activities - $18k and the Professional Education - $13k.

Legal Fees - $22k over budget

* The breakdown is:
  + Preclinical consortium documents finalized - $19k
  + Global Alliance documents finalized - $14k
  + Membership organization research - $7k
  + Annual state charity registration filings - $7k

Other Professional Fees - $20k over budget

* Biggest costs were for the Infantile Spasms Awareness project - $57k, Comedy for a Cure consultants - $30k, Web page hosting and programming - $11k.
* $17k of the $20k budget overage was for the Infantile Spasms spending (which was intentionally increased at year end to improve our Program to Admin/Fundraising ratio).

Biosample Repository Contracts - $63k under budget

* Van Andel facility payments were actually higher on a cash basis, but due to using accrual basis, less of that expense was reflected in 2016 (budgeting error).

Preclinical Consortium Contracts - $139k under budget

* Getting the program off the ground and finalizing documents took longer than anticipated – we did not get the first Consortium member to sign up until August.

2016 spending on programs exceeded the target of 75% at 76.5% due to focus on research and global partnerships, with the remaining spend on Development (13.3%) and Management & General (10.2%). This is an important element of our Charity Navigator rating.

Rich Gollub reported on the Charity Navigator rating. For 2015, reduced program spending dropped TS Alliance down to a 3 star rating; however, given the improvement in the ratio in 2016, we anticipate being back up to four stars in 2016 (and solidly remain there in 2017 given higher anticipated program spending in 2017).

Rich reviewed the balanced scorecard across the areas of strategic goals for the organization, with red, yellow and green lights indicate areas of strength and concern.

The Finance Committee reviewed finance policies related to reserve/crisis management policy and investment policy for operating funds. The intention is to maintain cash reserves at $700,000, consistent with previous practice.

As recommended by the Finance Committee, the Executive Committee passed a motion on March 2, 2017 to amend the TS Alliance Investment Policy for Operating Funds approved February 25, 2013 with the following text for the main 5th and 6th bullet points*.*

“• Operating funds may be held in money market instruments with the highest S&P, Moody, and/or Fitch principal stability rating. No cap on amounts covered by FDIC insurance. No more than 20% of gross operating funds to be invested in uninsured money markets. Money market deposit account balances are not to exceed the FDIC insured amounts with the additional limitation of the following paragraph.

• Balances held in the organization’s banking accounts may, however, exceed the FDIC insurance coverage by up to $1 million provided the financial institution maintains an S&P rating of A or Better.”

**Endowment Report Doug Loftus, Chair, Endowment Fund Board**

Doug Loftus noted that the fund is looking for members of the Eternal Flame Society; one becomes a member by naming the fund in their estate plan. The fund experienced strong growth in 2016, growing to $5.3 million as of end of February 2017. The fund is looking to grow its Board of Directors. The fund is reviewing tax regulations that affect the activities of the fund. The fund has created a named fund for Mike Augustine, and encourages contributions from board members.

**Committee Updates**

❖ Audit, Mike Caggiano, Chair

Rich Gollub provided the audit committee update, noting that the TS Alliance changed to a new audit firm for this year, Bond Beebe. The team is on schedule for a March 22 audit committee meeting to review the audit, followed by a Finance and Executive Committee meeting on March 24.

❖ Compensation, Cassie Carroll, Chair

The focus for 2017 is on employee retention and adding employee benefits that enhance the experience of the staff team.

❖ Development, Beth Dean, Chair

The committee has had two meetings this year focused on key annual goals and acting in a support role to assist April Cooper and Lisa Moss with events. The committee will identify a consultant for an upcoming meeting to train the board on “how to make the ask” and develop materials to support the board in these efforts.

❖ Global Relations, David Michaels, Chair

Dan Bloom dialed in from TS Alliance of Israel, and Andrew Duffy (ex-officio) join in person from Canada. Two new alliances formed at end of 2016, Mexico, and Thailand. The latter alliance serves the needs of 9 neighboring countries. The TS Alliance is in discussions with Hungary, the likely next Global Alliance.

❖ Government Relations, Debora Moritz, Chair

Many new advocates participated in March on the Hill, helping to achieve the goal of developing a strong advocacy team. There was a great deal of positive support from the House and Senate. There were numerous compelling stories from the day; the committee proposes displaying some on the website to encourage participation of advocates. Members of the committee noted that there was a risk of losing enthusiasm in Senate following meetings but before a letter circulates.

Mark Vieth drafted a TS Alliance policy statement entitled, “Advocating for Patients in ACA Repeal and Replace Debate.” The statement provides guidance for the staff to take action on (e.g., if CEO is requested to sign on to a letter from a partnering organization regarding positions on Affordable Care Act replacements). Mark and Kari would draft any call to action to advocates regarding health care legislative proposals, and send it to Tim Dills and Debora Moritz for review before sending out.

❖ Governance/Nominating, David Fitzmaurice, Chair

David Fitzmaurice noted that the TS Alliance had “pushed the pause button” mid-year 2016 on plans to change the membership structure of the organization. David and Tim invited a group of former board members to discuss potential alternatives. A new working group comprised of current and former board members will meet in coming months with the goal of coming up with a resolution to how to move forward regarding membership.

The Nominating Committee discussed an incredible slate of potential new candidates for recruitment to the board; applications are expected back by April 2017.

❖ Outreach, Rebecca Anhang Price, Chair

The Outreach staff are making steady progress on 2017 goals, and the committee had a rich discussion regarding suggestions for the 2018 World Conference.

❖ Science and Medical, Martina Bebin and Brendan Manning, Co-Chairs

*Update on PREVeNT Trial and International Research Conference on TSC and LAM*

The PREVeNT Trial has begun recruitment. A key issue to address is to ensure support to families to promote their 13 visits to the clinic. She received a grant of $10,000 from the Pediatric Epilepsy Research Foundation to support travel; in addition, B’Cureful has offered to provide financial support for additional travel needs in 2017.

A strong slate of speakers, including NIH directors, is slated to attend the International Research Conference on TSC and LAM.

*Approval of New TSC Clinic Directors and New TSC Clinic Committee Member*

On the recommendation of the Science and Medical Committee:

* There was a motion to approve new TSC Clinic Directors, Co-Director: Charuta Joshi, MD, Children’s Hospital Colorado, and Director: Anna Jeong, MD, Lurie Children’s Hospital, Chicago *(Moritz/Dean). The motion passed without dissent.*
* There was a motion to approve a new PAB Member: Charuta Joshi, MD, Children’s Hospital Colorado *(Hogue Duffy/Scroggins). The motion passed without dissent.*

**Other Issues Tim Dills, Chair**

None.

**Announce Date of Fall Meeting Tim Dills, Chair**

❖ October 12 (night) - 13, 2017, Hotel Monaco, 2 North Charles Street, Baltimore, MD

**Adjourn**

There being no further business, a motion was made to adjourn the meeting *(Dean/Moritz).* Meeting adjourned at 6:00 pm.

Respectfully submitted,

Rebecca Anhang Price, Secretary