**Tuberous Sclerosis Alliance**

**Board Meeting Minutes**

**December 12, 2018**

**DRAFT**

**In attendance:**

**Board Members:** Beth Dean (Chair), Chris Russell (Vice Chair), Jim Maginn (Treasurer), Cassandra Carroll (Secretary), Martina Bebin, Sara Chieffo, David Coit, Margaret Cox, Peter Crino, Bonnie Hogue Duffy, David Fitzmaurice, Rob Grandia, Tom Gwinn, Laura Lubbers, Adolfo Orive, Rebecca Anhang Price, Matthew Simonian

**Incoming Board Members (for 2019):** Matt Bolger, Heather Lens, Darcy Krueger, Sean Shillinger

**Staff:** Kari Rosbeck, Steve Roberds, Rich Gollub

**Call to Order & Chair’s Welcome, Beth Dean, Chair, Board of Directors**

Beth Dean called the meeting to order at 8:05 p.m. ET and confirmed a quorum of voting members. Chair Dean thanked the Board for a great year. She indicated that the TS Alliance is in good shape financially, and that we should finish strong based on our metrics. She also noted that the TS Alliance is meeting or exceeding its goals in most areas.

**Approval of the Minutes from the October 13, 2018 Board Meeting, Cassandra Carroll, Secretary**

A motion was made to approve the October 13, 2018 Board meeting minutes as written. (*Coit, Gwinn*). *The minutes were approved without dissent.*

**CEO Report, Kari Rosbeck**

Kari Rosbeck started with a discussion about the recent Infantile Spasms Awareness Week, which occurred December 1-7, 2018. She provided a report of the media outreach and advertising associated with same. A “Stakeholder Toolkit” was distributed to 26 organizations in the Infantile Spasms Action Network. The targeted advertising reached ER doctors (65 clicks, 22,757 impressions), family doctors (530 clicks, sent to 54,443 physicians), epilepsy professionals (6,046 attendees) and parents (12,540 clicks, 163,690 people reached, 90% women, 254,702 impressions). In addition, a radio media tour occurred with 13 radio interviews in a broad range of markets with a combined listenership of 632,400. Further, TV outreach included pushing the “STOP IS” video to 100 stations across the country. Ms. Rosbeck also noted community involvement, including FB Live presentations with a TS Alliance Reception with Drs. Bebin and Krueger and the Fike Family as well as interviews with Amy Miller (CNF) and Drs. Peter Crino, Orrin Devinsky and Shaun Hussain. There was also FB sharing of videos and graphics.

Ms. Rosbeck then presented about the American Epilepsy Society Meeting, which occurred November 30-December 4, 2018. At this event, a TS Alliance reception was held with 110 attendees. The following also occurred: TSC SIG, TS Alliance Exhibit Booth, TSC Clinic Directors Meeting, Industry Partner Meetings (Aquestive, Brain Sentinel, Eisai, Greenwich Biosciences, Mallinckrodt, Neurelis, UCB, Upsher-Smith), and Collaborative Meetings with other related organizations (Rare Epilepsies network (REN) Workshop, Epilepsy Leadership Council (ELC), and Infantile Spasms Action Network (ISAN)).

Thereafter, Ms. Rosbeck noted the top 8 initiatives for 2019:

* **Implementing Events Unique to 2019**

🡪45th Anniversary

🡪International TSC Research Conference

* **Launching the Research Business Plan and Meeting Milestones for Year One**
* **Expanding Volunteerism, Nationally and Internationally**

🡪TSC University now known as TSC Academy

🡪Government Advocacy, Federal and State

* **Continuing to Improve the Constituent Database**
* **Providing Support Programs and Services**

🡪Peer Support (TSC Connect)

🡪Regional TSC and LAM Conferences

🡪Community Alliances

🡪New Communication Tools to Reach More Constituents

* **Growing Depth of Global Alliances**
* **Improving and Facilitating Access to Medication**

🡪Vigabatrin (brand and generic)

🡪Afinitor (LOE date)

* **Increasing investment**

More specifically, with regard to the Investment to Accelerate Research goal, Ms. Rosbeck noted the following recent successes:

* Friends of TS Alliance Cultivation Event: November 13 in Denver with 22 attendees
* $1 million in New Gifts in 2018

🡪Cowlin Foundation: $900,000 over three years

🡪Wong Family Foundation: $100,000 over five years

* $1,092,500 in Requests Pending Toward $1.5 million for 2019

🡪Bill Watts: $500,000 over five years

🡪Greenwich Biosciences: $95,000

🡪Mallinckrodt: $40,000

🡪UCB: $207,500 over two years

🡪Annette Simmons: $250,000 over two years

**Science and Medical Committee Report, Steve Roberds and Martina Bebin**

Steve Roberds started by reiterating the focus of the TS Alliance Research Programs 🡪 Accelerating research and drug discovery through collaborative projects. He reviewed the slide showing the various phases of the various research programs, and the accompanying programs (Research Grants, Preclinical Consortium, Clinical Research Consortium, Biosample Repository and TSC Natural History Database).

Dr. Roberds noted an incline in TSC Biosamples by month from 2016-2018 with a steep incline following the World TSC Conference, reflecting that we are now beyond 700 samples. He further highlighted the projects supplying TSC Biosamples: (1) **TSC Natural History Database Project** (Texas Scottish Rite Hospital, Nicklaus Children’s Hospital Miami, Minnesota Epilepsy Group, Massachusetts General Hospital, Cincinnati Children’s Hospital Medical Center, UCLA, Washington University, University of Chicago, with contracts pending at UT Health Science Center at Houston, University of Alabama, Birmingham, and New York University); and (2) **Clinical Research Consortium Study Sites** (University of Alabama, Birmingham, Cincinnati Children’s Hospital Medical Center, Boston Children’s Hospital, UT Health Science Center at Houston, UCLA, Stanford, Minnesota Epilepsy Group, Washington University, Beaumont Hospital, Children’s Hospital Orange County, Children’s Hospital of Philadelphia, and Duke University Medical Center)

Dr. Roberds explained that the Consortium has run 21 compounds + 6 in-progress, with 4 planned. He noted that 9 companies have joined the Consortium since its inception.

Dr. Roberds then discussed briefly about a variety of scientific meetings that occurred at the American Epilepsy Society event, as follows:

* TSC science: Special Interest Group (SIG), preventing epilepsy mini-symposium, posters
* Clinical Research Consortium early epilepsy surgery group meeting
* TSC Clinic Directors meeting
* Rare Epilepsies Network (REN) meeting on rare epilepsies centers of excellence
* Scientific discussions with five companies, partnering discussions with more
* Epilepsy Benchmark Stewards and Learning Healthcare System meetings

Martina Bebin then discussed the status of the PREVeNT Trial. She noted that it is progressing nicely, particularly in the last quarter. She noted that they are up to 15 sites, and that 12 more are enrolling. Enrollment should be completed by December, 2019. She noted some of the early infants have completed their second year, and that they will be presenting some early data to the NIH in February, 2019 for review. Dr. Bebin expressed great appreciation for the TS Alliance and BCureful, indicating that the trial couldn’t have moved forward without the support of these organizations.

Dr. Bebin also noted that one of her more junior colleagues has started an “early surgery” project, reviewing data from babies that underwent epilepsy surgery before the age of 3. The idea is to jointly understand preventative therapy from both a medication and surgery standpoint, and the associated impact on developmental outcomes. Dr. Bebin thinks this collaboration should also open doors to involve more neurosurgeons in the Consortium. This group is in the early stages, but there is hope that this will be another successful endeavor with support from the Alliance.

**Treasurer’s Report, Jim Maginn and Rich Gollub**

Jim Maginn reported on the organization’s financial results through October 31, 2018.

In reviewing the Financial Dashboard, he pointed out that revenues are line with prior months. We are showing positive variances to budget in most revenue categories with the exception of “Other General Contributions” which is below budget mainly due to Appeals revenues running $28,000 under budget. The TS Alliance had total revenue of $3,815,000 through October 31, 2018, exceeding budget by $160,000. Expenses were at $4,614,000, which is ($296,000) under budget. The change in net assets was a negative ($799,000) for the period.

Mr. Maginn then reviewed the Balanced Scorecard as of October 31 and noted that most goals that have been on target (“in the green”) continue to be so in the latest report. The same can be said for those targets we are not currently meeting (‘in the red”) and those that are in-between (“in the yellow”). The organization is doing well in several categories:

* Meeting the goal of testing 10 compounds through the preclinical consortium.
* Increasing the number of peer-to-peer supports held throughout the year.
* Exceeding the amount of funds raised through special events.
* Generating sufficient revenues and managing expenses so that we do not exceed the budgeted deficit of ($474,426) for 2018.

The categories where we are not meeting our targets are related to:

* Growing the number of samples in the Biosample Repository
* Adding 3,000 new individuals and families to the constituent database
* Increasing programmatic spending to the dollar amount budgeted for the year

Rich Gollub discussed the October 31, 2018 and 2017 Statements of Financial Position, mentioning that although cash on hand had increased to $2,293,935 from the prior year, total assets are less, being $3,049,537 as of October 31, 2018 compared to $3,513,344 as of October 31, 2017. Liabilities are currently $447,414 versus $360,517 one year ago. Total net assets are less this year than last, although the breakdown between net assets with or without donor restrictions is now more heavily weighted toward net assets without donor restrictions ($1,510,408 without donor restrictions and $1,091,715 with donor restrictions as of October 31, 2018).

Mr. Gollub projected that the organization would have a strong closing 2 months, and he expected that total revenue would come in at $6,027,703, exceeding budgeted revenue by almost $338,000. This is assumes that the organization takes the full scheduled $335,000 Endowment Fund contribution, which may not be necessary. He expected total expenses to be $5,904,826, coming in $259,345 under budget. The current Projection for 2018 is a positive change in net assets of $122,128.

Mr. Gollub then proposed the GAAP basis 2019 TS Alliance Budget. Some of the key facets of the proposed Budget:

* Revenues of $6.64m, which is 10.1% more than projected 2018 revenues
* This budget is the first year of the new Research Business Plan and includes raising $1.9m of grant revenue in 2019 compared to the $1.2m raised this year
* Expenses of $6.63m, which is 12.3% more than projected 2018 expenses
* Increasing research spending to $3.5m accounts for the additional spending next year
* It is essentially a break-even budget, with a budgeted $5k positive change in net assets for the year
* Unlike 2018, there is no World TSC Conference planned for 2019, although there is an International Research Conference scheduled to take place in Toronto (which will reduce sponsorship and registration fee income, but also reduce the substantial conference and travel expenses of hosting the World TSC Conference)

He then went into some detail comparing the meeting/conference and travel expenses of 2019 to 2018, breaking out those expenses from the “World TSC Conference” line of the Statement of Activities, which includes all categories of expenses associated with hosting the Conference.

After Projecting that the organization’s cash position is expected to go from approximately $2.4m at the beginning of 2019 to $2.0m at the end of the year, Rich highlighted that there were several strategies the organization could employ to modulate spending if 2019 revenues do not appear to be coming in as expected in this first year under the new strategic plan.

The Board discussed whether it should opt out of taking most of the scheduled 2018 Endowment Fund contribution, if it is not needed to make the budgeted ($474k) deficit. The Board left the final decision to the Finance Committee but leaned toward preserving as much of this year’s contribution for use in future years if it is not needed so much this year.

There was also concern about having multiple years of deficits, and how that might impact our 4-star Charity Navigator rating. Rich Gollub thought that Charity Navigator’s current rating methodology would not penalize the organization for the deficits and instead more highly values an organization’s continual growth in programmatic spending.

A motion was made to approve the proposed 2019 Budget (*Tom Gwinn, Bonnie Duffy*). *The motion was approved without dissent.*

**Strategic Planning Committee Update, Rebecca Anhang Price**

Ms. Anhang Price provided an update regarding progress to date by the Strategic Planning Committee.

The Board reviewed the proposed OGSM (Objective, Goals, Strategies and Measures and Theory of Change documents in detail.

OGSM:

There was discussion, among other things, about how certain goals were revised to be more robust. For example, the “Improve Access and Quality of Care” strategies were rewritten to be more assertive, with assistance from Darcy Krueger. In the measures for this same goal, the third bullet-point was added re. “form a task group of key stakeholders (medical professionals, patients/families) to critically evaluate current TSC Clinic designation standards and recommend new organizational structure and requirements to the TS Alliance Board of Directors for approval and implementation by 2020.” Similarly, other bullet points for this goal were updated or added (*e.g.*, “conduct 7 studies between 2019-2023 focused on advancing evidence-based standards of care for TSC and/or TSC patient/caregiver-reported outcomes, using a combination of patient survey, existing data review, and prospective study designs,” as well as additional language related to “telehealth”).

For the “Educate and Mobilize to Increase Investment” goal, additions were made to the second bullet-point for measures, “grow the Endowment Fund to $10 million by 2023 and realize the maximum allowable annual contribution.” There were also measures added to this goal regarding crowd-funded events, as well as an awareness campaign to increase the number of contacts in the database as well as the number of impressions.

For the “Build and Strengthen Organization” goal, the first bullet-point for measures was revised to “maintain a 4-star CN rating and meet or exceed an 85/15 program/supporting expenses ratios by 2021 in accordance with the five-year Research Business Plan.” This was to ensure that all goals/measures aligned with the 5-Year Research Business Plan. In addition, another measure now more specifically states, “Grow Science and Medical team to 9.5 FTEs to accelerate research and improve quality of care by 2021 and corresponding staff (e.g., financial, fundraising, communications, support services) and infrastructure to support growth while maintaining 80% retention outside of retirements.”

For the “Support and Empower Constituents” goal, a minor revision was discussed regarding the sixth bullet-point regarding the implementation of “TSC University.” The name for this program will now be referred to as “TSC Academy.”

Theory of Change:

Ms. Anhang Price discussed that the idea behind this document is to define long-term goals, and then to likewise map backward in order to meet these long-term goals. It elaborates on the OGSM to further describe the nature of the individuals that are served by the TS Alliance and the populations that are served. She further noted that the “Assumptions” are the “heart” of the Theory of Change document. It explains why we do what we do. She then explained that the “Strategies/Activities” and “Leading Indicators” columns are carried over from the OGSM. Further, the “Outcomes” column shows anticipated short-term and long-term outcomes. Finally, the “Impact” column serves to describe the results of our efforts.

Rebecca Anhang Price requested two separate motions to approve the OGSM and Theory of Change documents (Attachments I-J) with the revision that “TSC University” will now be referred to “TSC Academy” in both documents.

OGSM -- (*Maginn/Chieffo*) *The motion was approved without dissent.*

Theory of Change document -- (*Crino/Simonian*). *The motion was approved without dissent*.

**Endowment Report, Rich Gollub**

Rich Gollub reported that the TS Alliance Endowment Fund had over $5.5m of net assets as of October 31, 2018, with most of those assets comprised of the Fund’s investment portfolio. He also reported that so far this year, the Endowment Fund has a negative change in net assets of ($187k) on its Statement of Activities. This is primarily due to the recent negative performance of financial markets impacting the portfolio.

**Other Committee Reports**

For Government Relations, Sara Chieffo indicated that the March on the Hill is already on everyone’s calendars, and that we are looking forward to similar bi-partisan support. She encouraged all board members to participate.

There were no other committee reports.

**Future Board Meeting Dates**

* + March 5-7, 2019, Embassy Suites DC – Convention Center, 900 10th Street NW, Washington, DC
  + June 5, 2019, 8 p.m. Teleconference
  + October 4, 2019, New York, NY

**Adjourn**

There being no further business, a motion was made to adjourn the meeting *(Lubbers/Anhang Price). The motion passed without dissent.* Meeting adjourned at 9:40 p.m. ET

Respectfully submitted,

Cassandra H. Carroll, Secretary