**Tuberous Sclerosis Alliance**

**Joint Executive and Finance Committee Meeting Minutes**

**November 2, 2018**

**DRAFT**

**In attendance:**

**Executive Committee Voting Officers:** Chris Russell (Acting Chair, by phone), Jim Maginn (Treasurer, by phone), Cassandra Carroll (Secretary by phone), Tim Dills (Immediate Past Chair)

**Executive Committee Member at Large:** Rebecca Anhang-Price (by phone), David Fitzmaurice (by phone), Darren Miles (by phone)

**Finance Committee Voting Members:** Jim Maginn (Chair, by phone), David Coit (by phone), Adolfo Orive (by phone), Chris Russell (by phone)

**Non-Voting Finance Committee Members:**  William Joseph

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

**Call to Order & Acting Chair’s Welcome, Chris Russell, Acting Chair, Board of Directors**

Chris Russell called the meeting to order at 11:03 a.m. (ET). A quorum of voting officers was confirmed for the Executive and Finance Committees. Mr. Russell explained that he is leading this meeting in Chair Beth Dean’s absence, while she recovers from a medical condition. He noted that the primary purpose of the meeting is to review and approve the Fiscal Year 2019 Budget and review and complete the Strategic Plan. Mr. Russell further noted that the agenda for this meeting has been condensed due to the productivity of the last Board meeting in Chicago.

**Approval of the Minutes from the August 29, 2018 Executive Committee Meeting, Cassandra Carroll, Secretary**

Cassandra Carroll requested a motion to approve the August 29, 2018 Executive Committee meeting minutes as written. (*Maginn/Russell*) *The minutes were approved without dissent.*

**Finance Report, Jim Maginn and Rich Gollub**

Approval of the Minutes from the October 12, 2018 Finance-Development Committee Meeting, Jim Maginn, Treasurer

Jim Maginn requested a motion to approve the October 12, 2018 Joint Finance-Development Committee meeting minutes as written. (*Coit/Russell*). *The minutes were approved without dissent.*

Review of Financial Reports

Jim Maginn reviewed the September 30, 2018 Financial Dashboard . Among other things, he noted the following: There has been a slight increase in major donors, but the numbers are impacted by the timing of past pledges. Any variance should be made up by year-end. It was noted that the Novartis contract will end this year, and that we might see impact from same next year. He emphasized that World TSC Conference sponsorships exceeded the budget and years past. He pointed out that Board contributions are down, and reminded Board members to make their donations by year-end. He noted that the TS Alliance has to this point opted to not take the approved 2018 Endowment Fund contribution, and that if it is not taken this year it will carry over for use by the TS Alliance in future years. He also noted that the programs portion of functional expenses through the 3rd quarter is better than what was reported for the prior quarter.

Mr. Maginn also reviewed the Balanced Scorecard. Among other things, he noted the following: There needs to be a push for the collection of more biosamples, and that increased staffing should help in this regard going forward. He noted that part of the reason why programmatic spending was running $280,000 below budget was because of an instance where a corporate partner wanted to contract directly with the testing lab, paying approximately $100,000 to the lab, instead of the standard process that is managed by the TS Alliance. There was some discussion as to how this variance should be portrayed on the Scorecard because it did not reduce the number of compounds being tested.

Controller and CFO Report:

Review of Statement of Financial Position

Rich Gollub reviewed the TS Alliance Statements of Financial Position as of September 30, 2018 and 2017. He pointed out the following changes from 12 months earlier:

* Cash and equivalents has increased from $1,700,265 to $2,206,034 as of September 30, 2018.
* Pledges receivable has decreased from $1,426,527 to $573,217, with the collection of the scheduled $500,000 pledge by the Engles Family Foundation this past summer being the reason for the lower receivable balance this year.
* Total assets decreased from $3,514,244 to $3,075,422 as of September 30, 2018.
* Total liabilities decreased from $558,669 to $514,642.
* Total net assets decreased from $2,955,575 to $2,560,780 but the amount of net assets without donor restrictions increased from $722,571 to $1,410,757 while the amount with donor restrictions decreased from $2,233,004 to $1,150,023.

Review of Updated Projections for 2018 as of September 30, 2018 and Cash Flow Projections for the remainder of 2018 and 2019

Mr. Gollub used actual numbers through September and projected revenue and expenses for the final quarter of 2018 to arrive at an overall Projected negative Change in Net Assets of ($324,385) compared to the budgeted negative ($474,426) change in net assets for the year, beating the 2018 Budget.

He stated that Revenues, projected at $5,661,158, would be slightly less than the $5,689,745 budgeted for 2018. Net Special Events Revenue, thanks to the strong collections at Comedy for a Cure and better than budgeted results of the Endurance Campaign and Facebook donations, is expected to exceed budget by $151,196. Major donor donation are expected to come in at ($134,177) below the budget of $1,210,740. Projected revenues assume that the full amount of the Endowment Fund contribution, $335,000 (made up of the $285,000 originally budgeted plus the Endowment’s recent pledge of an additional $50,000 to fund a research grant) will be taken by year end, even though none of the contribution has been needed so far this year.

Expenses are projected at $5,984,794, which is $179,377 less than the $6,164,171 budgeted for 2018. Most expenses are expected to end the year very close to budget, with the biggest variances being for Preclinical Consortium contracts, at ($143,139) under budget and the Natural History Database being ($84,956) under budget.

He also projected that there would be positive net cash flow for the 4th Quarter of 2018. As of October 1, 2018 there was $2,206,034 of cash on hand and he expected that to increase to $2,658,799 by year end. There are projected to be $1,990,182 of cash inflows compared to ($1,537,408) of outflows during that period.

Review of 2019 Budget Narrative and Proposed 2019 TS Alliance Budget

Rich Gollub proposed an essentially break-even TS Alliance Budget for 2019, ending the year with a $5,279 positive change in net assets. The Budget includes $6,639,227 of revenues and $6,633,948 of expenses. Revenues are budgeted to increase by 17.3% over projected 2018 revenues and expenses are budgeted to be 10.8% more than projected 2018 expenses. This is the first year under the new Strategic Plan and the 5-Year Research Business Plan, impacting both revenues and expenses. Grant revenues are budgeted to increase from $610,000 in 2018 to $1,900,000 in 2019. The level of research spending is budgeted to increase to a total of $3,500,000 in 2019.

In addition to the changes described above, Rich called attention to other significant variances from the current year to what is proposed for 2019:

* With the World TSC Conference held every 4 or 5 years, there will not be a repeat of the 2018 Conference next year. However there will be an International Research Conference in Toronto in 2019. Sponsorship revenue for 2018 was $758,000 and is budgeted at $190,000 for 2019.
* Growth of the Preclinical Consortium is expected to increase contract revenue from $1,130,000 in 2018 to $1,490,000 in 2019.
* Special Events revenue is also expected to increase from $1,450,000 this year to $1,640,000 in 2019.
* There will be no expenses for holding the World TSC Conference next year – a reduction of $688,000 compared to 2018.
* With the addition of a new position and having a Director of Preclinical Research for a full year, Staff related expenses are expected to increase from $2,010,000 this year to $2,290,000 in 2019.
* Spending on Preclinical Research is expected to increase from $1,080,000 to $1,770,000 in 2019.
* When excluding the substantial travel costs related to the World TSC Conference (all travel and meeting costs for the Conference are grouped together and not included in the “Travel” budget line item), other travel costs are budgeted to increase from $217,000 in 2018 to $409,000 in 2019.

It was pointed out that if revenues are not being generated as budgeted, a number of expenses can be scaled back or deferred until future years, so that the growth in research spending does not put the organization at financial risk.

There is projected to be a net outflow of cash during 2019, going from a cash balance of $2,658,799 at the beginning of the year, to projected cash of $2,259,360 as of December 31, 2019.

During discussion, the Committee members requested that additional details be provided to compare 2018 to 2019 costs for travel and meeting expenses, when the budget is presented to the full Board.

*Jim Maginn* moved to approve the Fiscal Year 2019 Budget on behalf of the Finance Committee, contingent on the following factors: confirmation of the $900,000 pledge from Cowlin Fund (impacting cash by $300,000.00 in 2019), (2) continuation of the 90-day cash flow projections through 2019, and (3) and detailed breakdown of travel expenses related to research conference. *David Coit* seconded the motion. *The motion was approved without dissent.*

*Chris Russell* also moved to approve the Fiscal Year 2019 Budget on behalf of the Executive Committee with the same language above. *Tim Dills* seconded the motion. *The motion was approved without dissent.*

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The meeting was briefly suspended from 12:13 p.m. (ET) to 12:32 p.m. (ET).

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**Strategic Planning Session, 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.

For the “Improve Access and Quality of Care” goal, the Strategic Planning Committee felt that we could be more aggressive. Two bullet points were added to the “Measures” for this goal, including language that the TS Alliance would “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” and “develop bi-annual curriculum (e.g. CME/CNE or TSC workshops at professional association meetings) that exposes TSC Clinic Directors and other health care providers to current evidence-based practices for TSC diagnosis, surveillance, and management.” It was noted that other minor changes were made to the wording in this section.

For the “Educate and Mobilize to Increase Investment” goal, the Strategic Planning Committee added a new measure, “Raise $56 million for research over the next five years,” to support the TS Alliance’s new research business plan. Another measure in this section, “Grow the Endowment Fund to $10 million and realize $500,000 in annual contribution by 2023,” was revised by the Board, as follows “Grow the endowment fund to $10 million by 2023 and realize maximum allowable annual contributions.” This edit was made to ensure that the measure complied with relevant endowment policies. Kari Rosbeck also noted that another measure, “Achieve additional 30 million impressions through new awareness campaign and 3,500 contacts to the database per year of the campaign,” was added to reflect the TS Alliance’s efforts to broaden its reach.

For the “Build and Strengthen Organization” goal, the board discussed at length the measure, “Achieve at least 8.7% annual increase in programmatic growth; 85/15 program/expense ratios with $13.8 million in revenue by 2023 while maintaining 4 star CN rating.” It was revised as follows, “Maintain a 4-star CN rating and meet or exceed an 85/15 program expense ratio by 2021 in accordance with the 5-year Research Business Plan.” Other additions to the strategies of this goal were also discussed, including, “Maintain database of current, reliable information of individuals with TSC their families and TS Alliance supporters complying with GDPR,” and “Serve as a leader in the rare disease community, sharing scientific and medical link of TSC to other diseases among peer diseases and disorders organizations, medical and related professionals, foundations, potential donors and constituents.”

The Board then reviewed the proposed Theory of Change document. Ms. Anhang Price explained that this is a strategic planning document that underlies everything we do as an organization. She noted that the “heart” of the document is the “Assumptions,” which describes TSC and other key aspects, and that the “Outcomes and Impact” section outlines the other key components of the Theory of Change.

Rebecca Anhang Price requested a motion to approve the OGSM and Theory of Change documents (Attachments P-Q) with revisions noted above. (*Dills/Maginn*) *The motion was approved without dissent.*

**2019 Planning Recap, Kari Rosbeck**

Ms. Rosbeck referred to the proposed Committee Assignments (2019), 2019 Board Meeting Dates, and Approval of 2019 Organizational Goals.

For the 2019 Organizational Goals, which were approved at the prior Board meeting, some additional revisions were proposed, as follows:

 Science and Medical, Paragraph 2 (Clinical Research and Clinical Care):

* a. Establish a process for Clinical Research Acceleration Fund to be implemented in 2020 to shorten study start-up times, support pre-trial patient studies and accelerate recruitment rates.

b. Establish a task force to develop a plan for assessing and improving quality of care at TSC Clinics, including use of telehealth.

Science and Medical, Paragraph 3 (TSC Preclinical Consortium):

c. Sustain at least seven pharma or biotech partnerships.

All of these revisions were explained, discussed and approved by the Executive Committee.

*Chris Russell* moved to approve the Updated 2019 Organizational Goals as reflected in Attachment R. *Cassie Carroll* seconded the motion. *The motion was approved without dissent.*

The Board also discussed the TS Alliance’s commitment to tribute Keith Hall by naming one of its grants after him. It was decided that the grant awarded to Christine Ochoa Escamilla, PhD this year would be known as the “Keith Hall Grant” because it best reflects Keith Hall’s mission. The Board also discussed that this grant is off-limits to any potential budget cut-backs, should that become necessary (although no such action is predicted).

**Action Items and Next Steps**

Note upcoming meeting as follows:

* + Circulate Committee Assignments for feedback from the Board.
	+ Circulate Strategic Plan to relevant committee members, explaining any Board revisions.
	+ Prepare to Present 2019 Budget with Board comments at next Board meeting.
	+ Inform Board about status of Cowlin Family Grant.
	+ Next Board Meeting Teleconference -- December 12, 2018, 8 p.m. ET.

**Adjourn**

There being no further business, *Chris Russell* moved to adjourn the meeting and *Cassie Carroll. The motion passed without dissent.* Meeting adjourned at 1:57 p.m. ET

Respectfully submitted,

Cassandra H. Carroll, Secretary