**Tuberous Sclerosis Alliance**

**Executive and Finance Committee Meeting Minutes**

**August 30, 2017**

*Approved by the Executive Committee October 13, 2017*

*Approved by the Finance Committee November 3, 2017*

**In attendance:**

**Executive Committee Voting Officers:** Tim Dills (Chair), David Fitzmaurice, Jim Maginn, Rebecca Anhang Price

**Executive Committee Member at Large:** Laura Lubbers

**Finance Committee Voting Members:** Jim Maginn, David Michaels, Margaret Cox

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

**Call to Order & Chair’s Welcome, Tim Dills, Chair, Board of Directors**

Tim Dills called the meeting to order at 8:04 pm and confirmed a quorum of voting officers. He noted that committees are preparing draft organizational goals and reviewing progress on 2017 goals. Tim requested that the EC submit any comments on the draft goals by September 21, in advance of the October board meeting. Updates on the 2017 progress will be included in October board meeting materials, and reviewed at the board meeting.

**Approval of the Minutes from the May 5, 2017 Joint Executive and Finance Committee Meeting, Rebecca Anhang Price, Secretary**

A motion was made to approve the May 5 Joint Executive and Finance Committee meeting minutes as written (*Fitzmaurice/Maginn*). *The minutes were approved without dissent.*

**Approval of the Minutes from the March 31, May 5 and June 28 Finance Committee Meetings, Jim Maginn, Treasurer**

A motion was made to approve the May 5, 2017 Joint Executive and Finance Committee meeting minutes as written (*Michaels/Cox*). *The minutes were approved without dissent.*

A motion was made to approve the March 31 Finance Committee meeting minutes as written (*Cox/Michaels*). *The minutes were approved without dissent.*

A motion was made to approve the June 28, 2017 Joint Executive and Finance Committee Meeting minutes (*Michaels/Maginn*). *The minutes were approved without dissent.*

**Brief CEO and CSO Reports, Kari Rosbeck and Steve Roberds**

Steve Roberds updated the Committees on outcomes from the research conference. There is a research conference summary posted on the TS Alliance website on the research conference page. A follow-up from the Patient-Focused Drug Development meeting is the draft of the Voice of the Patient report; a draft is well underway, and will be submitted to the FDA by the week of September 4 following review by James Valentine.

Preclinical Consortium: first epilepsy model animals were dosed one year ago, following preparation work for approximately a year and a half prior (including signing contracts, etc.). In the past 12 months, the first study validated the mouse model worked in the contract research lab and showed that rapamycin has strong effects at preventing epilepsy in this model, replicating what’s been seen in other labs. We’ve tested five different compounds from three companies and two compounds recommended by the academic working group. Testing has also identified new brain biomarkers that were not previously identified in the literature. There has also been a tissue collection for another company to do research on their target before they started testing drugs.

On the tumor side, we have sent TSC2-null tumor cells to a contract lab in France, where they implant the cells in mice and measure rate of growth in response to candidate drugs. We have been breeding mice for a model of TSC2 kidney tumors developed in Kwiatkowski’s lab. The mice are now 3 months old; they need to be 5 months old before dosing. As a result of all of these efforts, there’s been great programmatic spending, perhaps even going over on budgeted spend for the preclinical consortium.

The Natural History Database and Biosample Repository are slightly under budget on spending. We’ve budgeted for the maximum amount we could spend – e.g., maximum for all sites. However, each year, there are some sites that do not meet goals. For future years, we will budget more realistically (but less than the maximum allowable in the contracts with all sites). This year, we increased entries into the Repository for those who did not have a blood draw during their care by taking cheek swabs from these individuals. Cheek swabs are less costly than blood draws.

To keep all of these things going in 2018 will require continued spending and project management. In Preclinical, this year we’ve done epilepsy studies only, while next year, we also hope to do tumor studies. In Biosample Repository, will want to continue to collect samples. There are many good research grant applications. Will need to carefully prioritize across many promising opportunities for programmatic spending, including the World TSC Conference.

Kari Rosbeck gave the CEO report. The first generic vigabatrin went on the market this week (week of 8/29/2017). TS Alliance was notified of this development by CVS. The first generic is being made by PAR. For the first three months, government insurance will continue to cover the brand name. We are expecting four generics in the marketplace in the next month. Upsher-Smith is among them. Kari will be meeting with their brand launch team to talk with them about the unique needs of the TSC community and to encourage them to stay in contact with the community.

In preparation for the World TSC Conference, staff conducted a site visit in Dallas in August, posting a Facebook live video.

An anonymous donor has created the TSC Exploration Fund and provided a matching challenge grant of up to $100,000 for any gifts to the Keith Hall Memorial Fund.  Any gift already received or given through December 31 will be matched dollar for dollar.  As of the meeting, ~$74K had been raised for the Fund, so the $100,000 will likely be met.

April Cooper has done a great job of coordinating efforts for the endurance challenge (NYC marathon bib fundraiser). To date, this effort has raised $46K.

Kari and team are looking into how to better structure staffing for community outreach efforts. With Christen Bell going part time, there is an opportunity to look at where we have deficits in meeting the needs of the community, and have meaningful conversations with community leaders. The staff will bring a restructuring plan to the October Board Meeting.

**Treasurer’s Report on the July 31, 2017 Financial Statements**

National walk sponsorships are $50K under budget and other community events are running $41K below budget. Although additional events and fall walks are planned, unlikely to completely make up this shortfall. The TS Alliance received an unbudgeted $50K bequest from the Estate of Robert McBride and three unbudgeted donations of $20K or more.

Although preclinical drug screen spending will increase in the 3rd and 4th quarters, as pf June 30, overall program spending is $458k under budget.

Administrative costs will be closely monitored; also through June 30 fundraising is running $49k over budget and admin is $23k over budget. Increasing programmatic spending to budgeted levels will improve the ratios; ratios are currently within positive rating parameters of watchdog agencies.

Due to large pledges received over the past year and a half that have been designated for specific research areas, temporarily restricted net assets are high, at $2.6 Million. $1.1 million of this balance is for the Biosample Repository.

Recently, the TS Alliance has used a very narrow definition when applying expenses to temporarily restricted net asset categories, not applying any salary or related benefit costs to those categories. NIH and others do allocate salaries and related benefits to temporarily restricted net asset funding “buckets.” Rich sought feedback on whether a portion of Steve Roberds’ and JoAnne Nakagawa’s time (that corresponds to specific funding buckets) should be assigned to those categories, when releasing assets from those temporary restrictions. This would only be done in cases where the language in the donor’s grant would allow it. As an example, Dani Brunner, the consultant’s time, has always been allocated this way, since all of her time is spent on a restricted net asset project (the Preclinical Consortium) while Steve, in supervising her work has not. In regard to the question of who reviews these calculations, it was noted that reports to donors itemize the direct costs; and, in addition, auditors also review the temporarily restricted net assets schedule.

The committee discussed that it is preferable to move dollars from temporarily restricted net assets to unrestricted net assets in a conservative and appropriately justified manner. Committee members requested to see a breakdown of what we’re charging against these net assets, and seek input from auditors on the appropriate strategy.

Unrestricted net assets were much less as of July 31, 2017 than one year earlier ($634K versus $1.53M) primarily due to the net assets restricted by the $1.5M Engles Family Foundation gift. On the Statement of Activities, Rich noted that the travel expenses were up due to the March on the Hill and International Research Conference.

On the Endowment, the market has been up through August 25, seeing slightly over 7% return. The portfolio of the Endowment Fund is currently valued at $5,584,528 with the hope to continue to grow that for the rest of the year.

**Controller & CFO’s Report on the July 31, 2017 Projections**

Revenue is projected to be $10K better than budget. The one area that we’re hoping to iron out is Major Donors. A sizable $838K is still expected in last 5 months of the year. There are a few large donations in that number that Development Department is trying to lock down over the next 30 to 45 days. If these donations look unlikely to come through, then we will need to consider whether to give fewer grants. Expecting to come in $46K low for Expenses. Therefore, expect to come in with a deficit that is $56K less than the budgeted deficit.

Rich reviewed the proposed budget for the World TSC Conference, which will have an estimated 600 adult participants plus children, speakers, and staff. Revenue is estimated to be ~$755K (registration fees of ~$157K, sponsorships at $591K, other revenue at $7.5K), and expenses at ~$728K (including food, AV, lodging and transportation for speakers and staff, scholarships, and printing and promotions). If all goes according to this plan, there will be a net surplus of $27K. This proposed budget will be included in the 2018 TS Alliance budget. The staff will watch the numbers month to month and adjust accordingly.

A motion was made to accept the resolution to open a corporate credit card account with Capital One with Kari Rosbeck and Rich Gollub as signers in their roles as CEO and Controller with Tim Dills and Jim Maginn as signers on the account as Board Chair and Treasurer *(Maginn/Fitzmaurice). The motion passed without dissent.*

This would allow the organization to increase the interest rate on the $514k held in its money market account from 0.20% to 1.00% for one year and would provide a rebate of up to 1.25% on charges made on the cards.

If Capitol One follows through on all promises (limit of $150,000), the Alliance will get rid of its two American Express Cards.

A motion was made to amend the TS Alliance 401 (K) plan as follows *(Fitzmaurice/Maginn)*:

“RESOLVED, that the form of the Amendment presented to this meeting is to

adopt an amendment regarding the use of Forfeitures to reduce QNECS,

QMACS, and Safe Harbor Contributions. Such amendment will be effective on

the date it is adopted.

RESOLVED, that the Employer be, and hereby are, authorized and directed to execute any and all such documents and to perform any and all such acts as

may be necessary and proper to effect the foregoing.”

*The motion passed without dissent.*

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

Upcoming meetings are:

* Joint Finance and Development Committees – October 12, 2017 at 7:30 p.m. ET, Hotel Monaco, Baltimore, Maryland
* Executive Committee – October 13, 2017 at 4:00 p.m., Hotel Monaco, Baltimore, Maryland
* Joint Executive and Finance Planning Committee Meeting, November 3, 11 a.m. to 5 p.m. PT, Watt Companies, 2716 Ocean Park Blvd., Main Conference Room, 2nd Floor, Santa Monica, CA

**Adjourn**

There being no further business, a motion was made to adjourn the meeting *(Maginn/Fitzmaurice). The motion passed without dissent.* Meeting adjourned at 9:28 pm.

Respectfully submitted,

Rebecca Anhang Price, Secretary