**Tuberous Sclerosis Alliance**

**Joint Finance and Development Committee Meeting Minutes**

**Hotel Monaco**

**Baltimore, Maryland**

**October 12, 2017**

*Approved November3, 2017 by the Finance Committee*

In Attendance:

**Finance Committee Members (voting):** Jim Maginn (Chair), David Michaels

Finance Committee Members **(non-voting)**: David Coit, Chris Russell

**Development Committee Members:** Brendan Manning

**Board Members:** Andrew Duffy, David Fitzmaurice

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

Jim Maginn called the meeting to order at 7:49 p.m. No votes or formal actions were taken as it was determined that a voting quorum was not present for the Development Committee nor the Finance Committee.

**Review of the Finance Committee Minutes from the August 30, 2017 Joint Finance-Executive Committee Meeting**

Without a Finance Committee quorum, no vote was taken on the minutes.

**Review of the Development Committee Minutes from the June 28, 2017 Development Committee Meeting**

Without a Development Committee quorum, no vote was taken on the minutes.

**Review Financial Reports and Development Projections as of August 31, 2017**

Jim Maginn reviewed the financial reports and dashboard information as of August 31, 2017.

Total revenue and support for the eight months ending August 31, 2017 was $2,350,425, compared to budgeted total revenue of $2,179,246 for a positive variance of $171,179. Jim noted that Special Events revenue is currently coming in at $157,000 below budget. Shortfalls in the Walks and Other Community Events were more than offset by how much Major Donor and Appeals contributions exceeded their budgeted numbers. Major donor contributions currently are running $358,638 above budget and Appeals are $175,605 above budget due to the generous contributions in memory of Keith Hall, including the matching grant of up to $100,000 in his memory by the TSC Exploration Fund.

Expenses through August 31, 2017 were $3,227,641 compared to a budget of $3,201,834, with actual expenses being $25,806 greater than budget. Spending on the preclinical consortium has exceeded budget by $110,055 and we expect that trend to continue through year end. A good portion of those expenses are offset by contract income from industry partners in the Consortium. Travel costs have exceeded budget by $81,046 although that is partially offset by related training conference and exhibit costs currently running $39,816 under budget.

The change in net assets through August 31 is a negative ($877,216) which is better than the negative ($1,022,588) that was budgeted for the first 8 months of the year. The organization currently has total operating cash of $1,846,104.

Jim then reviewed the status of the 8 operating and financial goals being tracked by the Balanced Scorecard. Three of the goals are currently showing green lights for being on target, three with yellow lights for being on our watch list, and two with red lights, with goals that may be very difficult to reach by year end. The red lights were for mobilizing the grassroots community through budgeted special events and for increasing program spending to the level budgeted (which is only updated on a quarterly basis).

Rich Gollub then presented the Projection for the year. Total revenues are expected to increase to $4,706,038 and expenses to $5,334,122 for the full year, for a negative change in net assets of ($628,084). This Projected deficit would exceed the budgeted deficit of ($582,169) by $45,915.

There was interest expressed in providing the Committee with reports that would forecast out cash or the balance sheet, in addition to currently forecasting out the Statement of Activities. The Committee was also concerned that there was only $416,613 classified as unrestricted net assets on the August 31 Statement of Financial Position. Interest was expressed in developing a report that would estimate projected net asset classifications for future 3 month to 6 month periods.

**Presentation of the Draft 2018 TS Alliance Budget**

The Draft 2018 Budget includes $5.66 million of revenues and $6.16 million of expenses which net to a negative ($499,000) change in net assets. Both revenue and expenses are higher than a “normal” year due to the hosting of the World TSC Conference in Dallas, Texas next July. The budget includes $754 thousand of revenue and $733 thousand of expenses related to the Conference. The spending on the Conference would help continue the trend of spending a higher percentage of funds on program costs, in line with the Strategic Plan. The 2018 Budget would increase program spending to 80.5%, with the remaining 19.5% going toward development and general and administrative support expenses. With the almost the entire $1.5 million of revenue from last year’s pledge by the Engles’ Family Foundation reflected on the GAAP basis 2016 Statement of Activities, much of the spending is creating a net negative change in net assets this year and is having a similar effect on next year’s budget.

Rich reviewed revenue and expense areas showing the largest year-to-year changes from 2017 to 2018 but the Committee felt that it would be very helpful to also report on the budget’s effect on cash and on the breakdown between restricted and unrestricted net assets. Rich agreed to develop reports projecting out future cash flows and how net assets would be affected by the Draft2 2018 Budget.

There was also concern expressed with the cost of hosting the World TSC Conference and when the commitments would be obtained from sponsors, which is projected to bring in $591,000 of the Conference income. Although many of the sponsorships may not be finalized until early spring, it is possible to scale back on certain conference costs if attendance drops below the budgeted level. There was interest expressed in knowing what the savings or additional costs would be if we end up with either fewer or more attendees.

**2018 Finance Committee Goals**

The Finance Committee discussed the following goals for 2018:

1. Assist in strategies regarding investment of Operating Funds to optimize returns and minimize risk while adhering to the approved investment policy.

2. Utilize Charity Navigator and other charity rating services as a guide for the budget process and Form 990/financial statement presentation.

3. Assist the Controller/CFO with developing reporting procedures to properly track and segregate revenue and expenses for the 2018 World TSC Conference.

4. Use the Balanced Scorecard to monitor and periodically report on organizational progress toward attaining the monetary Measures of the Objectives, Goals and Strategies in the Strategic Plan.

5. Review initial draft of the FY19 Annual Budget by no later than October and approve the final budget to be presented to the Board at its December meeting.

**2018 Development Committee Goals**

The Development Committee discussed the following goals for 2018:

1. Continue to grow and promote “Unlock the Cure: ACT Now!” with a goal to focus fundraising themes on supporting current and emerging scientific initiatives such as Pre-Clinical Network, Clinical Research Consortium, TSC Natural History Database, Biosample Repository and TS Alliance Research Grants Program and raise $25 million from private and government sources by 2018.

a. Raise $500,000 in private funds and leverage $10 million from government sources direct to clinical research consortium projects.

b. Grow the President’s Council to a group of seven family members with substantial resources to jointly drive research forward through significant contributions to our Unlock the Cure campaign.

c. Raise $50,000 from crowdfunded research challenge or traditional direct mail appeal.

2. Increase major gifts and grants.

a. Hold three cultivation events resulting in $75,000 in revenue.

b. Grow industry partners to include three specialty pharmacies and three generic pharmaceutical companies.

c. Identify one new extraordinary donor to make a $200,000-plus gift.

3. Sustain 100% Board giving and obtain $50,000 in new major gifts from board solicitations.

4. Secure funding to support the 2018 World TSC Conference by raising $576,000 in sponsorships and contracts to underwrite majority of expenses and procuring 25 exhibitors including sponsors with a minimum of $15,000 in exhibit fees.

5. Engage the community through innovative events that create positive interactions between staff, board, volunteers, corporate partners and TS Alliance constituents and, as a result, increase participation and revenue.

a. Raise $1 million in Step Forward to Cure TSC walks with expense ratio of no more than 7%.

b. Raise $200,000 through online local community campaigns and endurance events with 5% expense ratio.

6. Grow the national brand of the TS Alliance through major events by involving supporters and influencers and raising substantial awareness of TSC.

a. Involve A-level talent by honoring nationally recognized celebrity at Comedy for a Cure; encourage attendance from TSC families nationwide; and maintain event revenue of $200,000 with expense ratio of 45%.

b. Host Art for a Cure in conjunction with the 2018 World TSC Conference to grow community participation online and at the event, expand public awareness by displaying winning artwork and achieve a revenue target of $50,000 with no more than 10% expense ratio.

**Discussion of 45th Anniversary Gala**

April Cooper began the discussion of the pros and cons of hosting a 45th Anniversary Event in 2019. She presented information on the amount of revenue and expenses generated by prior TS Alliance galas, going back to 2005. The prior galas brought in an average of approximately $335,000 each, with average expenses of $161,000 for an expense ratio of 48%. Possible locations for the event, which would bring in unrestricted revenue, were also discussed.

**Next Meeting**

The next Finance Committee meeting will be the Joint Planning Meeting with the Executive Committee on November 3, 2017 at 11:00 a.m. PST in Santa Monica, California.

**Adjourn**

There being no further business, the meeting was adjourned at 9:42 p.m. ET.

Respectfully submitted,

Rich Gollub

Controller and CFO