

**TSC Alliance Endowment Fund
Meeting Notes
July 19, 2022
DRAFT**

In attendance:

Board Members: Marion Adams (Chair), Michael Augustine, Rita DiDomenico, Tim Dills, Jim Maginn, Hal Tearse, Paul Waxlax

Staff: Cynthia Arcuri, Lisa Moss, Kari Rosbeck

Welcome by Marion Adams

Marion Adams called the meeting to order at 6:02 p.m. ET and confirmed quorum of voting members.

Approval of TSC Alliance Endowment Fund Minutes from the March 3, 2022 meeting

Mike Augustine asked if the members had reviewed the minutes and if there were any objections or comments. There being none, *Augustine* motioned to approve the meeting minutes and *all agreed without dissent*.

Review of the June 30, 2022 Endowment Fund Financial Statements

Hal Tearse gave the financial report. On the SFP, staff does an awesome job budgeting and tracking finances. He highlighted change of net assets (\$1.118M) primarily due to investment portfolio being down 17-18% YTD along with the financial industry. The investment committee discussed the market the day prior.

On the SOA, Cynthia created a new dashboard that shows the variances in general revenue and expense categories. Revenue is currently under budget due to no contributions from major donors coming in yet this year. Operating expenses were under budget due to reduced fundraising fees due to reduced services of Graham Pelton starting a few months ago. Endowment pledged an additional \$20k in March 2022 on top of the \$50k approved in the 2022 budget for World TSC Conference Scholarships. YTD Unrealized gains and losses totaled a little over \$1M and hopefully will gain by end of year. Cynthia did add a line for restricted vs. unrestricted assets so the board could see how much of our net assets are without restrictions.

Second Quarter 2022 Endowment Fund Portfolio Review

Doug Loftus provided thorough review of the investments the previous day during the Investment Committee meeting. Marion Adams walked the board through the Second Quarter Portfolio Review. The portfolio is in-line with the guidelines and the portfolio is positioned well. Second quarter went from \$6.4 million to \$5.6 million as of June 30, 2022, a decline of 11.87%. Longer term performance and compared to blended market benchmark and the overall Endowment Fund compared to benchmark (almost 14%) YTD Endowment 14% vs 15% of benchmark. It's been a touchy market to be in and given the environment, the Investment Committee and Endowment board are pleased with the job Doug is doing.

Highlighted asset classes currently being used. Target allocation 80% equity/20% fixed income. This is long-term in nature but liquid enough to make contributions to the operating side. The Investment Committee is evaluating and can quickly change as needed. Investment Committee will continue to monitor. Fixed income a little higher and yesterday \$238,000 was approved by Investment Committee to be removed from fixed incomes, as the annual gift to the TSC Alliance, which will move the allocation back in compliance. \$70,000 contribution to operating for World TSC Conference was transferred in April.

New Prospective Endowment Fund Board Members

Two prospects were identified during nominating committee. Rita reached out to them after Kari Rosbeck made an introduction. Rita sent an email and follow-up today for a meeting to discuss the Endowment Fund and board members – David Johnston and Will Cooper, Jr. Next step, Rita will reach out via text. Will have more to report. This is also time of year to reach back out to Howard Pattis and hopefully his health issues will be resolved by now. And will pursue further. IN 2023, Mike Augustine and Hal Tearse will be rolling off.

Progress of the 2022 Endowment Board Goals and discussion of Endowment Board Goals for 2023

2022 Progress

1. Market planned giving vehicles, including gift annuities, plus additional giving ideas such as qualified charitable distributions, and donations of appreciated property, with a goal of placement of stories in *Perspective* on planned giving, highlight one story in e-newsletter and program ads for major TS Alliance events.
 - a. *There was an ad in the virtual program book for Comedy for a Cure.*
 - b. *Ad included in the WC program book. Endowment materials will be included in TSC Alliance booth and in conference bags.*
 - c. *Story was included in Perspective that came out in the beginning of 2022.*
2. Implement plan to convert prospects identified in the Research Campaign Study into Endowment Fund contributions or planned gifts as part of the Capital Campaign, especially during this time (COVID-19) where donors are re-evaluating long-term financial plans.
 - a. *A letter has been sent initially to anyone has indicated they were interested in planned giving.*
 - b. *Currently have an Endowment newsletter in development which would include a story and mention of Endowment Fund, which would be sent to prospects identified in the Research Campaign Study.*
3. Conduct virtual meetings with ten TSC Alliance Endowment Fund Major Donor prospects and secure five new planned giving bequests and begin tracking new expectancies with a goal of adding \$250,000 in 2022.
 - a. *Due to World Conference planning, this will be the focus of the second half of 2022.*
 - b. *We currently have a meeting planned on August 10th with a prospect.*
4. Calculate the annual contribution to the TSC Alliance according to the investment spending policy and approve a budget by October 2022 for 2023. Maintain record of cumulative budgeted contributions not paid to the TS Alliance and held for future programmatic use.
 - a. *This will be calculated in the 3rd quarter of 2022.*
5. Hold quarterly meetings to review investments and make adjustments to reflect market changes.
 - a. *We are holding quarterly investment committee meetings to review the portfolio.*
6. Continue having an Endowment liaison serve on the operating Nominating Committee to cultivate and vet potential Endowment Fund Board candidates keeping in mind those that reflect the diversity of our community.
 - a. *Rita DiDomenico is an active member of the Nominating Committee and has three prospects she is cultivating.*

2023 DRAFT Goals

1. Market planned giving vehicles, including gift annuities, plus additional giving ideas such as qualified charitable distributions, and donations of appreciated property, with a goal of placement of stories in *Perspective* on planned giving, highlight one story in e-newsletter and program ads for major TS Alliance events.

2. Continue to implement plans to convert prospects identified in the Research Campaign Study into Endowment Fund contributions or planned gifts by conducting at least 10 meetings with prospective donors with a goal of adding \$250,000 in 2023.
3. Calculate the annual contribution to the TSC Alliance according to the investment spending policy and approve a budget by October 2023 for 2024. Maintain record of cumulative budgeted contributions not paid to the TS Alliance and held for future programmatic use.
4. Hold quarterly meetings to review investments and make adjustments to reflect market changes.
5. Continue having an Endowment liaison serve on the operating Nominating Committee to cultivate and vet potential Endowment Fund Board candidates keeping in mind those that reflect the diversity of our community.
6. Stay up to date on tax laws that would impact planned or charitable giving for the Endowment Fund.

There was a discussion to include analysis of sunset exemption that will end in 2025 which previously allowed \$11-12 million exempt from estate tax. Estate tax will be cut in half. Charitable planned gifts kick in much sooner than planned gifts. With the bills pending, stalled by Sen. Machin, there may be deficit in capital gain rate and appreciated assets would be more valuable to us.

Committee will review annual goals again in October and vote to approve at that time in case any changes occur.

Status of Fundraising Campaign to Accelerate Research

Lisa Moss presented on the Research Campaign. The operating entity received a \$2.5 million gift from the Ramesh and Kalpana Bhatia Foundation and have raised \$11,635,239. Foundations are half of our contributions. To date we have raised 29% of the campaign goal of \$40 million.

There have been 83 donor meetings, 56 ongoing, 8 requests totaling \$4.165 million received 6 pledges totaling \$3,315,500. We have a few large gifts hanging out there and will be focus of the Fall. Mike Augustine inquired if Graham-Pelton have been effective. Lisa commented that consultants were worth the money and helped us in the largest campaign in our history. There is a specific way these things are done and helpful to work with consultant doing a campaign of that nature and put our materials and speaking points in line with how major donors have been approached previously. Graham-Pelton have shared market knowledge and their experience.

Kari Rosbeck commented that we went from a \$5 million to \$10 million organization, created new tools and systems and completely changed the way we raised money as an organization. Additionally, we had a donor that commented early in the campaign the TSC Alliance was at the crossroads of capacity and inclination. Based on what we have been able to accomplish, including two new compounds from the preclinical entering clinical trials, more donors are inclined to see their dollars at work.

Future Meetings Schedule:

- October 21, 2022 – 1:30 PM ET – Silver Spring, MD

There being no other business, *Waxlax* motioned to adjourn the meeting at 6:36 p.m. ET. *Tearse* seconded the motion.

Respectfully submitted,
Kari Luther Rosbeck, President and CEO