

**TSC Alliance Endowment Fund
Board of Directors Meeting
Wednesday, July 26, 2023
APPROVED 10/13/23**

In attendance (all on Zoom):

Board Members: Marion Adams (Chair), Michael Augustine, Rita DiDomenico, Brittany Smith, Tim Dills, Jim Maginn

Staff: Cynthia Arcuri, Lisa Moss, Rachel Wojnilower

Pre-Meeting Update

The Endowment Fund will receive funds due to an expectancy from Magdalena Lutsky, client of Mike Augustine. The Fund is to receive approximately 1/3 of IRA in process. Another gift is to come from trust assets but may be held in probate – to be \$330,000-350,000 this calendar year.

Chair's Opening Remarks and Introductions

Marion Adams called the meeting to order at 1:04 p.m. ET. A quorum of voting members was confirmed.

Approval of the Minutes from the March 2, 2023

Mike Augustine brought forth a request to approve the Minutes from the March 2, 2023 meeting. *Jim Maginn* moved to approve the meeting minutes. *Tim Dills* seconded the motion. *The minutes passed without dissent.*

Review of Financial Statements as of June 30, 2023

Cynthia Arcuri provided a brief review of the financial statement of the Endowment Fund as of June 30, 2023. The Statement of Financial Position shows \$36,000 in cash and \$6million+ for investment balance. Gift annuities payable has balance from Magdalena and will remove later this year after death certificate is received. Total net assets were \$5.9 million as of June 30, 2023.

General contributions of \$12,000 for the year which is under budget, but we have an expectancy that occurred earlier this year and we will be receiving funds from this. Market change is favorable with \$97k of realized gains and \$341k of unrealized gains.

Due to the positive market trends so far in 2023, change in net assets at 6/30/23 was \$470k compared to (\$1.118 million) at 6/30/22.

The annual contribution to the TSC Alliance is scheduled to be made in July for \$238k and was approved in the 2023 budget. *Bob Groves* moved to award the Funds to the TSC Alliance. *Jim Maginn* seconded the motion. *The motion passed without dissent.*

Investment Portfolio Report as of Q2 2023

Marion Adams provided an overview of Q2 performance. Doug Loftus met with the Investment Committee earlier this week. Positive quarter with main portion of the Endowment Fund up 5%.

Overall performance versus market benchmark shows short term Q2 and YTD are behind the benchmark by 30 basis points, there is no concern. The market has been very narrow with a handful of stocks distorting the market index. Our diversified portfolio is still serving us well and meeting our goals. Later in this meeting we will discuss adding an asset class.

Prospective Endowment Fund Board Members

Rita DiDomenico presented on the current Endowment Fund Prospects. The list has changed a bit from the previous meeting.

- **Will Cooper:** no response about interest
- **David Johnston:** connected in May and he has interest, may listen into calls this year; Rita will reach back out at the end of the summer.
- **Mark Schaengold:** on many boards, Rachel Wojnilower's dad, businessman, very interested, may listen into calls this year; Rita will reach back out.
- **Megan DellaCosta:** young, has TSC and interested in giving back, BA in Nursing

In 2024 there will be 3 open slots (Hal Tearse and Mike Augustine), so up to 3 slots will be able to be filled.

Progress on 2023 Goals and Discussion of 2024 Goals

Cynthia Arcuri presented the following progress on the 2023 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 TSC Alliance events.
 - *The Donor Relations Department has implemented a new Endowment Newsletter contract and plans to add a free will service online through contracts with Stelter.*
 1. *Update from Lisa Moss: Including Endowment ads in program books for Comedy, Research Conference, Perspective. Stelter program that will be discussed later.*
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.
 - *There is a \$1 million proposal pending for a gift to the Endowment Fund for Research Campaign. Have had multiple touch-points throughout the year and have submitted a proposal. Will continue to pursue.*
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 TSC Alliance and held for future programmatic use.
4. Hold quarterly meetings to review investments and make adjustments to reflect market changes.
 - *Quarterly investment meetings have been scheduled for January 19, April 19, July 24, and October 19, 2023.*
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 and adding at least 2 new board members in 2023 for terms beginning in 2024.
 - *Rita DiDomenico continues to serve on the Nominating Committee. Rita shared there are at least three interested prospects she is cultivating.*
6. Staying abreast on any new or changing tax laws that impact charitable giving.

Cynthia presented the following *Draft* 2024 Goals, which are similar to the 2023 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 to place articles in *Perspective* on planned giving, highlight one story in eNewsletter and include program ads for major TSC 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 five meetings with prospective donors with a goal of adding \$250,000 in 2024.
 - This was a change from 10 to 5 in 2023 but with the same dollar amount goal.
3. Calculate the annual contribution to the TSC Alliance according to the investment spending policy and approve a 2025 budget by October 2024. Maintain record of cumulative budgeted contributions not paid to the TSC Alliance and held for future programmatic use.
4. Hold quarterly meetings to review investments and make adjustments to reflect market changes.
5. Continue to have an Endowment Fund Board liaison serve on the Operating Board's Nominating Committee to cultivate and vet potential Endowment Fund Board candidates, keeping in mind those who reflect the diversity of our community, and add at least two new members in 2024 for terms beginning in 2025.
6. Stay informed of tax laws that impact planned or charitable giving for the Endowment Fund.

Cynthia asked for any comments or changes. It was agreed that they will be reviewed again and approved at the October meeting.

Status of Campaign to Accelerate Research

Lisa Moss updated the Board on the Investment to Accelerate Research. As of June 30, \$542,477 of the \$5,085,000 goal for 2023 has been raised. As of May, \$13,168,145 of the \$40 million campaign goal has been raised cumulatively. The pie chart shows the breakdown of where the gifts have come from. "Campaign progress by gift level" chart shows the goals for the dollars and number of donors needed to get to \$40 million. We are at 33% to goal and happy with the progress.

Lisa also compared two companies, Giving Docs and FreeWill, a free-for-user will creation platform and estate planning toolkit for donors. It could be embedded into the website platform. Lisa met with both companies and created test wills. The platforms are very similar in the ease of creating a will, marketing tools and dashboards, and both are valid in all 50 states (with caveats for California). The biggest difference is that Giving Docs is integrated with Stelter and FreeWill is a less seamless integration but is possible. Mike Augustine reviewed test wills from both companies and both seemed fine as basic wills. Mike explained that in California and maybe a few others states, if it doesn't align with state laws it perhaps might be considered not valid; perhaps if there is state specific language, it should be checked before recommending it. Lisa and Mike will schedule a meeting with each company to set up a time to discuss California in more detail. Both were equally easy to use and have reminders to get witnesses, signatures, and notaries to sign. Cost is very different – Giving Docs is \$8,500/year with first year discount of \$2,500; FreeWill is \$12,000/year. Lisa is currently having discussions with FreeWill regarding a more competitive price. In summary, both products seem similar enough that the price discrepancy seems high. Lisa can share the sample wills she created if anyone is interested.

Upcoming Meeting

In person on October 13, 2023, time TBD (TSC Alliance HQ, Silver Spring, MD)

Other Business

TSC Accelerant Fund

Marion Adams brought forth discussion of the TSC Accelerant Fund. Investment policy lists allowable investments, and today we are looking at adding an additional asset class. Doug Loftus manages the investments and provides quarterly updates.

The Accelerant Fund is coming out regardless with a first closing in the fall. Very exciting to Marion! John Nicholson is an MD, investor and has put a group together a group to do investments to benefits

TSC. They would like the Endowment Fund to consider an investment in the Fund. It seems that it will help TSC, will share profits with operating side of TSC Alliance, and would look good for us to be invested so they can get additional investments. Non-liquid investment so we will not put a lot in, but do think we could make money too.

We want to add the ability for Doug and firm to put *up to 10% into VC/PE asset class* specific to this Fund. If approved, we will continue to get additional information and discuss the investment again at a future meeting. Could be around \$200,000, with smaller amounts at the beginning and more to be called upon over time.

The Endowment Investment Committee is working on adding proposed language to allow these types of investment. Proposed language is as follows:

Venture Capital / Private Investments: Partnerships and/or investments directly related to advancing the TSC Alliance mission of finding a cure for TSC while improving the lives of those affected. These investments can include research, early stage company formation, licensing opportunities, etc.

Brittany Smith asked if we would require that there be additional investment. Doug Loftus' team is reviewing the documents provided by the Accelerant Fund.

Jim stated this is very risky fundraising which is very different from current investments. It is a satisfying purpose but the dollars are going to be at high risk. It would require getting over the hurdle that this is something we should be investing in versus the credibility that the Accelerant Fund wants. Marion explained that if it were not for TSC, we would not be considering it due to the size of our fund. It would be a small percentage due to liquidity needs.

Rita asked about potential new donations that would come in – Marion said we would look at it but not allow for donations with restrictions. We could not take money specific to investing in this pool of money. Jim would like to hear more about the Fund and stated that we will need to always be able to explain why this is a point of investment.

Next up will be to review Doug's team's due diligence and recommendation, then bring in Accelerant Fund team for a presentation to the full Endowment Fund Board. There is hesitation to make a change in the Investment Policy at this time before hearing more. We will call an additional meeting if it seems it is necessary to meet before October.

Rainy Day Fund

Cynthia Arcuri brought forth the topic of formally transferring the \$334,625 in Rainy Day Funds to the TSC Alliance. The Rainy Day Fund are the dollars allocated to the TSC Alliance that haven't come over in previous years, but are always available. After speaking to auditors and tax team, it would be fine to record the transfer of Rainy Day funds in the financial statements. The Endowment financial statements would record the contribution/transfer as an expense and "Due to NTSA" and the NTSA financial statements would record it as revenue and "Due from Endowment." The funds/investments would not need to be liquidated until truly necessary. There are no plans at this time for NTSA to need additional funds this year.

Marion Adams brought forth a motion to approve the recognition of the Rainy Day Fund contribution. *Brittany Smith* moved to approve. *Mike Augustine* seconded the motion. *The motion passed without dissent.*

Adjournment

There being no further business, *Tim Dills* moved to adjourn the meeting at 1:56 p.m. ET. *Mike Augustine* seconded the motion.

Respectfully Submitted,
Rachel Wojnilower, Chief of Staff
Cynthia Arcuri, CFO