

**TSC Alliance**  
**Annual Membership Meeting**  
**Friday, October 13, 2023**  
**Approved: December 11, 2023**

In Attendance:

**Board Member in-person:** Bill Joseph (Chair), Derek Bauer, Matt Bolger, Chip Burkhalter, David Coit, Jonathan Goldstein, Rob Grandia, Dana Holinka, Jessica Krefting, Darcy Krueger, Heather Lens, Brittany Smith, Laura Marks, Sean Shillinger, Paul Waxlax

**Board Members on Zoom:** Julie Blum, Lisa Carlton, Julian Gangolli, Tanjala Gipson, Lesley Holmes, Shafali Jeste, Patroski Lawson, Kristi Lengyel, Mustafa Sahin, Vanessa Vasquez, Tara Zimmerman

**Endowment Fund Board members on Zoom:** Marion Adams, Jim Maginn

**Members:** Frances Briones, Danielle Clark, Deb Joseph, Mark Keezer, John and Jordan Richards, Lauren Shillinger, Mark Spotts

**Staff in-person:** Ayat Abi, Cynthia Arcuri, Liz Cassidy, Jaye Isham, Madison Larrimore, Shelly Meitzler, Lisa Moss, Ashley Pounders, Steve Roberds, Kari Rosbeck, Katie Smith, Gail Saunders, Rachel Wojnilower

**Staff on Zoom:** Ryan Beebe, Anne Wolfe

**Call to Order & Convene the Annual Membership Meeting**

Bill Joseph, Chair, called the Membership Meeting to order at 4:00 pm ET.

**Report of the Nominating Committee**

Matt Bolger, Governance Committee Chair, presented slate of board candidates for 2024.

The proposed renewing board members are:

- Derek Bauer, Chip Burkhalter, Tanjala Gipson, and Jessica Krefting.

The proposed new board members are:

- Frances Briones, Andrew Sperling, and Mark Spotts.

**Report of the Membership Vote**

Lesley Holmes, Secretary, reported the votes from the Membership. Fifty-one proxy ballots were received electronically or at the TSC Alliance office by the deadline of October 12, 2023. Fifty votes in favor of the full slate of candidates to the Board of Directors as presented were received. One ballot was received that did not accept or reject the slate of candidates as presented. The bylaws of the National Tuberous Sclerosis Association, Inc., d/b/a TSC Alliance, require that a quorum consists of no less than 10 percent of the active membership. The membership vote provided well above the minimum number of required ballots and represents a quorum.

**Motion to Ratify the Vote of Membership**

Bill Joseph requested a motion to ratify the vote of the membership. *John Richards* moved to ratify the vote of the membership and *Sean Shillinger* seconded. *The motion passed without dissent.*

**Presentation of the Constituent Survey**

Matt Bolger, Strategic Planning Committee Chair, summarized the purpose and results of the constituent survey, including the demographics of the respondents. Just over three quarters of the respondents are female, which has also been true in prior waves. The vast majority are caregivers, most often parents of individuals with TSC. Four in five primary caregivers indicate that TSC was

diagnosed within the first two years of life. Individuals with TSC are almost equally a mix of independent, dependent, and semi-dependent. The largest proportion of provider respondents continues to be neurologists followed by researchers or scientists. Behavioral problems, sleep disorders, and psychiatric issues are reportedly the most challenging to manage. Sixty-four percent of respondents are using a TSC Clinic. For those who do not, the top reason was that no clinic is within a reasonable driving distance.

People who are satisfied and those who have frustrations with the organization tend to respond to the survey, but ambivalent people often do not. Some people are upset that the organization does not provide recommendations for doctors or provide direct care, which we are not equipped to do. The TSC Alliance website and TSC Clinics are sources regularly used most often. TSC offerings such as the World Conference and March on the Hill rank highly among our constituents.

A member made a comment about breaking down the age of diagnosis for higher ages in smaller increments so we can obtain more data in future surveys.

### **Chief Executive Officer's Report**

Kari Luther Rosbeck, President and CEO, provided a report to the membership. Kari called for the entire TSC Alliance staff to stand and be recognized. The organization has invested over \$11 million since 2019 to accelerate research. Kari also highlighted key progress made on the research business plan outcomes through August 2023, including seventy-four compounds tested in the preclinical consortium and 2,562 biosamples collected through mobile collection.

Most recently, the TSC Alliance hosted the 2023 International Research Conference in Washington D.C. with over 250 participants. We have also held workshops on reproductive and perinatal health and newborn screening. We continue to assist families with quality of care. For example, the number of families who needed assistance with medication access has gone down this year, which was our goal. Four hundred and sixteen families were supported through our support navigators in 2023. We also launched reproductive and perinatal health initiative objectives.

The TSC Alliance has made strides globally with our global alliance partnerships. The organization will meet our \$3.4 million goal in October for the research campaign. In terms of digital statistics, we had 570.3 million media impressions after four media releases. We are top-rated by Charitywatchdog organizations—our program to fundraising/admin ratio is 78.6% to 21.4%. The organization also has 80%+ job retention for employees.

In 2024, we will be celebrating fifty years of promise and progress at the 50<sup>th</sup> Anniversary Gala in NYC. In January, we will also be launching the new TSC Alliance website, new strategic plan, and new vision and mission statements.

### **Other Business and Adjournment**

There being no other business, *Heather Lens* motioned to adjourn the annual membership meeting. *Jonathan Goldstein* seconded. The membership meeting adjourned at 4:32 pm ET.

**TSC Alliance**  
**Board of Directors Meetings**  
**Friday, October 13, 2023**  
**Approved: December 11, 2023**

In Attendance:

**Board Member in-person:** Bill Joseph (Chair), Derek Bauer, Matt Bolger, Chip Burkhalter, David Coit, Jonathan Goldstein, Rob Grandia, Dana Holinka, Jessica Krefting, Darcy Krueger, Heather Lens, Brittany Smith, Laura Marks, Sean Shillinger, Paul Waxlax

**Board Members on Zoom:** Julie Blum, Lisa Carlton, Julian Gangolli, Tanjala Gipson, Lesley Holmes, Shafali Jeste, Patroski Lawson, Kristi Lengyel, Mustafa Sahin, Vanessa Vasquez, Tara Zimmerman

**Endowment Fund Board members on Zoom:** Marion Adams, Jim Maginn

**Members:** Frances Briones, Danielle Clark, Deb Joseph, Mark Keezer, John and Jordan Richards, Lauren Shillinger, Mark Spotts

**Staff in-person:** Ayat Abi, Cynthia Arcuri, Liz Cassidy, Jaye Isham, Madison Larrimore, Shelly Meitzler, Lisa Moss, Ashley Pounders, Steve Roberds, Kari Rosbeck, Katie Smith, Gail Saunders, Rachel Wojnilower

**Staff on Zoom:** Ryan Beebe, Anne Wolfe

**Call to Order & Opening Comments**

Bill Joseph called the meeting to order at 4:32 pm ET. Bill acknowledged Dr. Sahin for being elected by the National Academy of Medicine for demonstrating outstanding professional achievement and service. Dr. Sahin thanked the Board and noted that this recognition of work is what he and his team have accomplished as a group and he wanted to thank all of the patients and families for contributing as well.

Bill also commented on all the hard work and dedication of the Board. We are tackling big issues and making progress in hitting our goals. Bill also wanted to thank all of the staff who then run with the ideas that come out of the Board meetings and that we are all working together to improve our TSC community.

**Approval of 2024 Organizational Goals**

Kari summarized some of the recent changes made to the proposed 2024 organizational goals. Bill Joseph requested a motion to approve of the FY24 Organizational Goals as finalized. *Derek Bauer* motioned to approve the organizational goals and *Matt Bolger* seconded. *The motion carried without dissent.*

**Departing Board Tributes**

Board members offered tributes to our departing board members: David Coit, Rob Grandia, Dana Holinka, and Tara Zimmerman. Tributes for Peter Crino and Diane McSwain were made during lunch.

**Approval of Minutes of the June 5, 2023 Meeting**

Lesley Holmes requested approval of the minutes from the June 5, 2023 Board meeting. *Rob Grandia* motioned to approve the minutes. *Jessica Krefting* seconded. *The motion passed without dissent.*

**Endowment Board Report**

Marion Adams provided an update. The current endowment is valued at around \$5.6 million. The portfolio is performing inline with the goals of the organization. The Endowment Fund has been doing

due diligence on the TSC Accelerant Fund for several months about doing a possible investment. The Board approved new language for this type of asset and plan to make a \$250,000 commitment at the first closing of this fund. We think the fund will benefit all those living with TSC and the TSC Alliance. The Endowment Board approved its 2024 budget and goals. Two new board members (David Johnston and Mark Schaengold) were added and two left (Mike Augustine and Hal Tearse). Marion will serve one more year as the Chair.

### **Treasurer's Report**

Brittany Smith provided the Treasurer's Report. We are currently tracking to our expectations for revenue in 2023. Expenses are a similar story where we are tracking a little above budget. From a cash perspective, we ended August with \$2.3 million in cash and we are expected to be at \$2 million at the end of December.

### **Science and Medical Committee Report**

Shafali Jeste provided an update on the Science and Medical Committee's recent work.

#### *Discuss and Vote on Postdoctoral Fellowship and Research Grant Awards*

The Committee received a lot of applications for post-doctorate fellowships and research grants. These grants can have a significant impact on our research and medical community. Dr. Jeste noted that Dr. Sahin's first grant ever was from the TSC Alliance and helped to jumpstart his career. It can often be challenging for researchers to get started. We have three post-doctorate fellows for whom the Science and Medical Committee recommends to receive funding. Steve Roberds discussed the slate of applicants:

- *Stephanie Dooves, PhD – role of EGF signaling in astrocyte-neuron interactions in TSC.*
- *Joochwan Kim, PhD – identify metabolite markers for diagnosis and treatment of TSC kidney tumors.*
- *Luis Martinez, PhD – rescue of epilepsy gene therapy in a mouse model of TSC.*

Steve also discussed the candidates for receipt of research grants:

- *Lena Nguyen, PhD – translational control mechanisms in TSC-associated epilepsy.*
- *Alternate candidate: Jeffrey Calhoun, PhD – novel TSC2 assays for variant of uncertain significance resolution at scale.*

Shafali requested a motion to award Drs. Dooves, Kim, Martinez, and Nguyen with \$150,000 in each in research funding over two years, with Dr. Calhoun named as an alternate. *Matt Bolger* motioned to approve the funding awards and *Darcy Krueger* seconded. *The motion passed without dissent.*

#### *Discuss and vote on new TSC Clinic Applications*

The Committee has recently altered the clinic application process to make it more user-friendly, both from the review process and applicant process. The Committee has made some recommendations:

- Three new clinics are recommended to be added as TSC Centers of Excellence ("COE") going forward, bringing the total to 15 COEs: Corewell Health East (Danielle Nolan, MI); Seattle Children's Hospital (Stephanie Randle, WA); Cleveland Clinic (Ajay Gupta, OH).
- We are working with four clinics to potentially become COEs in the future: Children's Hospital of Orange County (Donald Phillips, CA); CHLA TSC Clinic (Vijay Vishwanath, CA); UNC TSC Clinic (Jamie Capal, NC); Mercy Comprehensive TSC (Mohammed Ilyas, MO). One new clinic is also recommended: UTSW (Charuta Joshi, TX).
- One clinic is recommended to be on provisional status for one year: MN Epilepsy Group (Doug Smith, OH)

- Several TSC Clinics are recommended to be placed on continuing status to be re-evaluated within six months (a number of these current clinics did not complete the application process at all or it was not deemed acceptable). These include:
  - Children’s Wisconsin, Donal Basel, WI
  - Penn State Health/Hershey Medical Center, Sita Paudel
  - Swedish TSC Clinic, Marcio Sotero de Menezes, WA
  - Loma Linda University, Stephen Ashwal
  - UCSF Benioff, Ali Mostajeelean, CA
  - UF Health TSC Clinic, Hans Shuhaiber, FL
  - Nicklaus Childrens, Paula Schleifer, FL
  - John Hopkins All Children’s, Stacie Stapleton, FL
  - University of Chicago, James Tonsgard, IL
  - University of Louisville TSC Clinic, Samir, Karia, KY
  - NYU, Josiane LaJoie, NY
  - Akron Children’s, Michael Kohrman, OH
  - Childrens Hospital of Pittsburgh, Shelley Williams, PA
  - Virginia Commonwealth University, Lawrence Morton, VA
  - Arizona Pediatric Neurology, Vonodh Narayanan, AZ
  - Children’s National, William McClintock, DC
  - Moffitt Cancer Center, Sepideh Mokhtari, FL
  - University of Illinois, Akira Yoshii
  - Med Atlantic Epilepsy and Sleep Center, Pavel Klein, MD
  - Cardinal Glennon Children’s, Himanshu Kaulas, MO
  - Montefiore Medical Center, Nagma Dalvi , NY
  - Dayton Children’s Hospital, Rajkumar Agarwal, OH
  - University of Pennsylvania and CHOP, Katherine Nathanson, PA

A Board member asked whether those in the community should still refer families to clinics if they are no longer COEs. There was a discussion about these changes being internal designations for the time being. And, if there is a change in status for any clinic, that clinic will have an opportunity to work with the TSC Alliance to get back to its previous designation.

*Sean Shillinger* motioned to approve the slate of COEs. *Dana Holinka* seconded. *Derek Bauer* and *Jessica Krefting* abstained. *The motion passed without dissent.*

*Jessica Krefting* motioned to approve the slate of TSC Clinics. *Derek Bauer* seconded. *Shafali Jeste* abstained. *The motion passed without dissent.*

*Matt Bolger* motioned to approve placing The MN Epilepsy Group on provisional status. *Jessica Krefting* seconded. *The motion passed without dissent.*

*Rob Grandia* motioned to approve the slate of continuing clinics (continuing status for six months to allow time for them to submit approved paperwork and then vote on status in February 2024).

*Jonathan*

*Goldstein* seconded. *Julie Blum* abstained. *The motion passed without dissent.*

### **Strategic Planning Committee Report**

Matt Bolger provided an update on this Committee. The framework we use is the OGSM and theory of change. A big part of the discussion on this Committee was for whom are we doing this strategic plan: prospective parents, caregivers, and adults with TSC. The plan is aligned with the

organization's vision to create a future where everyone affected by TSC can live their fullest lives. The Committee has set forth short-term and long-term outcomes for Accelerating Research, Improving Access and Quality Care, and Supporting and Empowering Constituents. Each goal has a set of strategies and measures to assist in accomplishing the goal.

Bill Joseph requested a motion to approve the 2024 Strategic Plan (OGSM and Theory of Change). *Laura Marks* motioned to approve the Strategic Plan. *Derek Bauer* seconded. *The motion passed without dissent.*

### **Governance Committee Report**

Matt Bolger called for a motion to approve the slate of officers for 2024. The nominations are Chair: Bill Joseph; Vice Chair: Paul Waxlax; Secretary: Lesley Holmes; Treasurer: Brittany Smith. Since Peter Crino's term on the board is over, there will be no immediate past chair in 2024. *Jonathan Goldstein* motioned to approve the slate of officers for 2024. *Derek Bauer* seconded. *The motion passed without dissent.*

### **Global Relations Committee Report**

Darcy Krueger provided an update on the Global Relations Committee. A major pillar for this Committee is expanding our support of Global Alliances, and two major initiatives fall under that: (1) expanding the natural history database to add international participants, particularly in India, Canada and Mexico; (2) working on restructuring the clinic recognition process, involving similar adjustment for our global clinics and COEs in partnership with Global Alliances. We also continue to partner with TSCi to coordinate efforts and hold joint workshops. The Committee ran out of time today to discuss the equally important pillar regarding focusing on what do we do in support of TSC patients and families where we do not have TSC representation. Our plan is to discuss this more fully in January and add it as a goal.

### **Government Relations Committee Report**

Chip Burkhalter provided the update. The Committee reviewed the TSCRP funding and whether the appropriations bill for FY24 will be passed by the Senate. There was also a discussion about the upcoming March on Capitol Hill and whether we will increase our ask to \$12 million. Overall, the organization's advocacy for federal and state funding was a success this past year. We had, in particular, great success in receiving state funding in Alabama, Maryland, and Missouri and discussed how we could replicate that success in other states. We also established a task force for looking into telehealth capabilities for those in rural locations.

### **Outreach Committee Report**

Dana Holinka updated the Board on recent efforts of this Committee. Most of the discussions have been around the restructuring of our community alliances. Ninety-one people have signed up for new roles and we have onboarded twenty-six new volunteers for training through TSC Academy. We are also in the process of updating the volunteer manual. The hope is to have all community alliance regions up and running by the end of 2024. Dana noted that having the Science and Medical and Outreach Committees coming together more to discuss assisting families has been wonderful.

Derek Bauer provided an update on the new SUDEP initiative. He also noted that the Committee has spent time on clinic designation changes and how that might impact our community. We need to be sure we are proactive about that and communicating correctly with our community about those changes.

### **Research Campaign Steering Committee Report**

David Coit updated the Board on status. We have reached \$16.5 million so far as of October 10, 2023, with about half of that coming from foundations. This is pretty much what we expect for the quiet phase and we are continuing to go after some of the higher donors during this phase. This is a staff-driven process and the organization has done a great job of executing. Raising \$40 million is a big lift as it is often much harder to raise research dollars since there is not a concrete deliverable to offer. David noted that he is very impressed by these numbers. Our community trusts us to be good fiduciaries. David also thanked Jim Maginn for this work on this Committee.

### **Next Meetings**

- December 11, 2023 at 8:00 ET –Via Zoom
- February 27-29, 2024 – Doubletree Crystal City
- June 3, 2024 at 8:00 ET – Via Zoom

### **Other Business and Adjournment**

There being no further business, *Derek Bauer* motioned to adjourn the meeting. *Rob Grandia* seconded the motion and the meeting was adjourned at 6:01 p.m. ET.

Respectfully submitted,  
Lesley Holmes, Secretary