**Tuberous Sclerosis Alliance Board of Directors Meeting**

**Annual Membership Meeting Minutes**

**October 13, 2017**

**Approved: December 6, 2017**

**In attendance:**

**Voting Members:** Tim Dills (Chair), John Bissler, Sara Chieffo, Beth Dean, David Fitzmaurice, Bonnie Hogue Duffy (phone), Laura Lubbers, Jim Maginn, Brendan Manning, David Michaels, Debora Moritz, Julie Scroggins and Matthew Simonian

**Endowment Board Members:** Doug Loftus, Jim Achterhof

**Board Nominees:** David Coit, Peter Crino, Rob Grandia, Dana Holinka, Chris Russell and Tara Zimmerman

**TS Alliance Members:** David Parkes, John Richards, Jocelyn and Frank Cenna

**Guests:**

**Staff**: Kari Rosbeck, Rich Gollub, Steve Roberds, Dena Hook, Jaye Isham, Lisa Moss, April Cooper, Jo Anne Nakagawa, Katie Smith and Tori Bunn

**Call to Order & Convene the Annual Membership Meeting, Tim Dills, Chair, Board of Directors**Tim Dills called the meeting to order at 4:36pm ET.

**Report of the Nominating Committee, David Fitzmaurice, Nominating Chair**

David reported that the Membership ballots were mailed to request member votes for the slate of candidates to include new Board Members and renewing board members. The ballot also included a vote to approve Bylaws amendments, to update Membership terms and to halt the requirement for Lifetime Members to annually state their intent to remain classified as Lifetime Members.

David introduced the Slate of Board Nominees for 2018:

Proposed New Board Members

David M. Coit

Peter B. Crino, MD, PhD

Robert Grandia

Dana Holinka

Adolfo Orive

Chris Russell

Tara C. Zimmerman

Proposed Renewing Board Members

Cassandra “Cassie” Carroll

Beth Dean

**Report of the Membership Vote, David Fitzmaurice**

David reported that ballots were mailed on August 28, 2017 and sent to 544 active members of the organization. The deadline for proxy votes to be received was October 12, 2017 and 102 proxy ballots were received at the Tuberous Sclerosis Alliance office by the deadline. When voting for the full slate of candidates presented, there were 102 votes in favor and no votes against. When voting for the bylaws amendments, there were 92 votes in favor, 2 votes against, 4 votes withheld and 4 left blank.

The bylaws of the National Tuberous Sclerosis Association, Inc. d/b/a Tuberous Sclerosis Alliance require that a quorum consist of no less than 10 percent of 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, Tim Dills, Chair**

Tim thanked the members for attending and welcomed the new and renewing directors. He asked if there were any members present that would like to cast their vote. John Richards voted yes to adopt the slate of candidates and the bylaws amendments. Jocelyn Cenna had already voted via ballot and thanked the Board of Directors and Staff for all that they do.

A motion was made to approve the slate of new board members *(Richards, Cenna*). The motion passed without dissent.

**Chief Executive Officer’s Report Kari Luther Rosbeck, President and CEO**

Kari talked about the TSC families, adults with TSC, Physicians, Researchers, Board and Staff as a committed community.

Kari showed the drug discovery pipeline illustration and highlighted the PREVeNT Trial as the first preventative trial for epilepsy in the United States. She thanked Julie Scroggins and Bcureful for raising $145,000 to cover travel funds for families with infants enrolled in the trial.

Kari then reviewed the progress made in 2017:

***Accelerate Research***

* We have 2114 individuals enrolled in the Natural History Database.
* We have 350 samples collected in the Biosample Repository and have a goal to collect 1000 blood samples and 200 tissue samples by the end of 2018.
* Our goal is to fund Research Grants at $450,000 per year and we are projected to pay out $491,675 in 2017.
* There are 6 industry partners in the Preclinical Consortium: Anavex, GW, UCB, PIQUR, Takeda, and one anonymous.
* Abstracts for posters highlighting the Preclinical Consortium will be presented at the American Epilepsy Society Annual Meeting, Society for Neuroscience Annual Meeting, and NORD’s Rare Disease and Orphan Products Breakthrough Summit.
* There are 7 sites running PREVeNT trial launched December 1.
* We hosted an Externally-Led Patient-Focused Drug Development Meeting with the FDA on June 21.
  + Prior to the meeting, we received 1,309 responses from 57 countries to an international survey of individuals with TSC and LAM and caregivers
  + In person attendance was 98, including parents/caregivers, adults with TSC and LAM, members of the FDA, NIH, and industry
  + Live webcast received 666 views from 27 countries, and the recording posted on our website via YouTube has received 290 views
  + *Voice of the Patient* to be submitted to FDA as a guideline   
    for the development of new treatments for TSC
* The 2018 TSC and LAM Research Conference was held in DC in partnership with the LAM Foundation.
  + More than 200 attendees from 27 countries
  + Keynote speaker: David Sabatini, PhD
  + Featured Dinner Presentations: Walter Koroshetz, MD, Director, National Institute of Neurological Disorders and Stokes and James Kiley, MS, PhD, Director of the Division of Lung Diseases of NHLBI
  + Scientific presentations included several new potential drug targets, novel mechanisms in mouse models and novel discoveries in cell signaling, TAND and healthcare impacts of TSC, insights into current clinical trials and studies including two looking at early biomarkers for autism.

***Support and Empower Constituents:***

* 8,332 constituents added to our database since 2014.
* 1,852 trainings and 58 school meetings as of 9/30/17
* 1,675 individuals/families reached by a Clinic Ambassador as of 9/30/17
* 52 new volunteers as of 9/30/17 totaling 225 since we launched the strategic plan in 2014
* 4 new Global Alliance/Partners: TS Canada ST, TS Alliance of Mexico, TS Alliance of ASEAN Foundation, and 1 pending: Hungarian Foundation for Tuberous Sclerosis
* 14,588 in peer supports as of 9/30/17

***Mobilize to Increase Investment***

* 24.2 million impressions on website, more than doubling the 10 million goal
* Special events projected to raise $1.3 million this year, falling short of the $1.5 million goal
* Endowment contributions have increased from $197,200 in 2013 to $216,000 in 2018. The goal was to achieve $250,000 in annual contributions by 2018
* Unlock the Cure ACT NOW has raised $403,145 YTD and a total of $4,696,963 since launching in 2015
* Overall, Unlock the Cure has raised $9,384,534 since 2011

***Build and Strengthen Organization***

* For 2018 our goal is to achieve at minimum 3% annual increase in program expenses with balanced budget; 80/20 program/expense ratio with revenue of $5.5 million by 2018 while maintaining a 4-star Charity Navigator rating
* 2018 draft budget includes: 17.5% Program Growth; $5,664,744 revenue, $6,164,171 expense; 80.5% program / 19.5% admin and fundraising; 4-star Charity Navigator rating, BBB Wise Giving Recognition, Platinum Level Guidestar Charity
* We received a $1.5 million pledge that was recognized in 2016 and show a budgeted loss of $500,000 being spent from that gift in 2018.
* 15 national/international professional meetings were attended or sessions led by staff
* 7 new Board members were nominated for 2018
* Staff retention held steady at 86.67% (goal: 70%).
* Staff reviewed Emergency Back Up Plan for every department and every position, short- and long-term
* Developed a restructure plan for 2018 to strengthen community services and community engagement
* Constituent survey to launch in January 2018 to provide input to next strategic plan

***Impacting Our TSC Community through Upcoming Conferences***

* October 14: Transition Workshop in New York, in partnership with Child Neurology Foundation (CFN), The Arc, and MassMutual
* November 4: Transition Workshop in San Diego, in partnership with CNF, The Arc, and MassMutual
* July 26-29, 2018: World TSC Conference, Dallas, TX. Four educational tracks, 76 confirmed expert speakers (16 international), networking opportunities, day camp, scholarships for families

***What’s the One Thing* You *Can Do?***

* Participate in the upcoming constituent survey.
* Participate in event committees and local community events.
* Recruit future board members with ability to raise substantial major gifts.
* Identify and cultivate a new donor, especially one who might join the President’s Council.
* Identify sponsors for 2018 World TSC Conference.
* Crowd fund sponsorships.

**Adjourn**

A motion to adjourn was made at 5:08pm (*Bissler, Parkes*). The motion passed without dissent.

Respectfully submitted,

Lisa Moss, Senior Director, Donor Relations

**Tuberous Sclerosis Alliance**

**Board of Directors Meeting Minutes**

**October 13, 2017**

**4:30 pm ET**

**DRAFT**

**In attendance:**

**Voting Members:** Tim Dills (Chair), John Bissler, Sara Chieffo, Beth Dean, David Fitzmaurice, Bonnie Hogue Duffy (phone), Laura Lubbers, Jim Maginn, Brendan Manning, David Michaels, Debora Moritz, Julie Scroggins and Matthew Simonian

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**Chair’s Welcome and Report, Tim Dills**Tim called the meeting to order at 5:09pm ET. A quorum was present.

Tim thanked everyone for taking the time out of their schedules to attend the meeting and expressed his appreciation for having been part of the board. He commented that there is a great slate of incoming board members who he is looking forward to working with. He said he is impressed by the incredible volunteers and amazing group of people he has been involved with through this role and thanked Kari and the staff for their commitment to the TSC community.

**Departing Board Tributes, Sara Chieffo, David Parkes**

David Michaels and Debora Moritz were acknowledged for their contribution to the Board and the TS Alliance over the years. They both received awards and heartfelt thanks.

**Board Approval of Meeting Minutes from June 7, 2017, Tim Dills**

Tim asked for a motion to approve June 7, 2017 Board Meeting minutes (*Chieffo, Scroggins*). There was no discussion. The motion passed without dissent.

**Endowment Report, Doug Loftus**

Doug announced that there will be two new board members next year with Mike Augustine and Hal Tearse joining the Endowment Board and a goal to recruit two additional members in 2018. Doug indicated that the fund is at $5.8MM in assets. $328k will be distributed this year to the TS Alliance and that $104k has been transferred to date. An additional $75k was approved to be transferred to the TS Alliance to find an additional research grant. The Endowment Fund Board has authorized a $285k contribution from the fund for the 2018 operating budget.

**Treasurer’s Report, Jim Maginn**

Jim reported that the financials are strong but the restricted assets are high and unrestricted assets are low. The Engles gift is good for science and increased our restricted net assets; however, additional staff and expenses are required to administer larger scientific investments, which can create a challenge with a reduced amount of unrestricted net assets to make day-to-day expenses. We have seen reduced revenue from walks which is unrestricted revenue, so there are less available funds for operations. April Cooper is working to improve this situation significantly while Rich and the staff are making sure we do what we need to in order to meet goals. The Endowment Fund is helping out with distributions and increasing grant funding. The 2018 budget will be presented on Nov. 3 to the Executive Committee. Next year we will be hosting the World TSC Conference which Kari and the team are feeling good about.

**Committee Updates and Items for Vote, various presenters**

**Governance / Nominating Committee Report, David Fitzmaurice**

David thanked everyone for contributing to a great list of nominees this year and remarked that 6 out of 7 nominees were present. He introduced the 2018 TS Alliance slate of Board officers: Beth Dean (Chair), Chris Russell (Vice Chair), Cassie Carroll (Secretary), Jim Maginn (Treasurer), and, by virtue of his office Tim Dills (Immediate Past chair). David also shared that Rebecca Anhang Price has agreed to Chair the Strategic Planning Committee and requested a one year extended term.

A motion was made to approve the 2018 TS Alliance Board officers (*Simonian, Bissler*). The motion passed without dissent.

A motion was made to approve a one year extended term for Rebecca Anhang Price to Chair the Strategic Planning Committee (*Scroggins, Lubbers*). The motion passed without dissent.

**Science and Medical Committee, Brendan Manning**

Brendan shared that this year there were 60 LOIs submitted which is the most submitted in a given year in the history of the TS Alliance. The committee made its recommendation for funding two Research Grant Awards, with the possibility of adding a third. The committee recommended funding the grant applications submitted by Michael Evans for $150,000 (Ablative Therapies) and Peter Davis for $74,895 (Brain Network Biomarkers). The Evans grant will be funded by the Keith Hall Memorial Fund. There are two additional highly scored grants that are alternates and will be discussed in November.

A motion was made to fund the grant applications submitted by Michael Evans for $150,000 and Peter Davis for $74,895 (*Moritz, Bissler*). The motion passed without dissent.

TSC1 and TSC2 Variant Databases are used as a reference by many geneticists, and testing companies refer to this database as well. It would be beneficial to have funds to add curated data with cost sharing between the U.S. ($117,610) and UK (£88,658). Peter Crino emphasized what an incredible resource this is.

A motion was made to approve funding of $117,610 for the TSC1 and TSC2 Variant Databases (*Bissler, Moritz*). The motion passed without dissent.

A motion was made to approve the following 17 new TSC Clinics (*Lubbers, Moritz)*

* Arkansas Children's, Little Rock, AR; Debopam Samanta, MD
* Children's Hospital Los Angeles/USC, Los Angeles, CA; Tena Rosser, MD
* Associated Neurologists of Southern Connecticut, a member of the St. Vincent's
* Multispecialty Group, Fairfield, CT; Nicholas Blondin, MD
* Johns Hopkins All Children's Hospital, St. Petersburg, FL; Stacie Stapleton, MD
* H. Lee Moffitt Cancer Center, Tampa, FL; Sepideh Mokhtari, MD
* University of Illinois at Chicago, Chicago, IL; Akira Yoshii, MD, PhD
* University of Maryland, Baltimore, MD; Peter B. Crino, MD, PhD
* Children's Mercy Hospital, Kansas City, MO; Mohammed Ilyas, MD
* Cardinal Glennon Children's Hospital/ St. Louis University School of Medicine, St. Louis, MO; Vikram Prakash, MD
* Levine Children's Hospital, Carolinas Healthcare System, Charlotte, NC; Katherine C. Van Poppel, MD
* Duke Medical Center, Durham, NC; Klaus G. Werner, MD
* Akron Children's Hospital, Akron, OH; Poonam Bhatia, MBBS, MD
* Rainbow Babies and Children's Hospital at University Hospitals Cleveland Medical Center, Cleveland, OH; Asim Shahid, MD
* VCU Health System, Richmond, VA; Lawrence D. Morton, MD
* Seattle Children's Hospital, Seattle, WA; Stephanie Randle, MD
* Children's Hospital of Wisconsin, Milwaukee, WI; Donald Basel, MD
* Neural Clinic, Merida, Yucatan, Mexico; Joao Garcia, MD

The motion passed without dissent.

A motion was made to approve the TSC Clinic Director change and new

Co-Director at New York Presbyterian / Columbia University Medical Center. Former Director, James Riviello, MD, relocated to Texas Children’s Hospital, Houston. (*Scroggins, Simonian*).

* Cigdem Akman, MD, as Director
* Elena Gonzalez, MSN, RNC, CPNP, as Co-Director

The motion passed without dissent.

A motion was made to approve new PAB nominees (*Moritz, Dean*).

* Debopam Samanta, MD, Little Rock, AR
* Tena Rosser, MD, Los Angeles, CA
* Nicholas Blondin, MD, Fairfield, CT
* Stacie Stapleton, MD, St. Petersburg, FL
* Sepideh Mokhtari, MD, Tampa, FL
* Akira Yoshii, MD, PhD, Chicago, IL
* Vikram Prakash, MD, St. Louis, MO
* Mohammad Ilyas, MD, Kansas City, MO
* Klaus Georg Werner, MD, Durham, NC
* Asim Shahid, MD, Cleveland, OH
* Poonam Bhatia, MD, Akron, OH
* Lawrence Morton, MD, Richmond, VA
* Stephanie Randle, MD, Seattle, WA
* Donald Basel, MD, Milwaukee, WI
* Joao Garcia, MD, Merida, Yucatan, Mexico

The motion passed without dissent.

**Compensation Committee, Cassie Carroll**

The Employee Handbook and Whistleblower Policy were reviewed with employment council to make sure all policies are consistent with applicable laws. Recommendations were taken from council and small changes were made to existing policies.

A motion was made to approve the updated Whistleblower policy (*Dean, Moritz*). The motion passed without dissent.

A motion was made to approve the updated Employee Handbook (*Dean, Chieffo*). The motion passed without dissent.

**Audit Committee, Rich Gollub**

There was discussion of cyber liability insurance and the consensus was that maintaining coverage through a cyber liability insurance rider is sufficient. A partner from Withum, our audit firm, discussed changes in nonprofit accounting standards that will take effect on January 1, 2018. Instead of three types of net assets, there will be two: those with donor restrictions and those without donor restrictions. When this change is made, the prior year numbers will need to be adjusted to be consistent with the presentation required by the new standards since we provide two years of reporting on our audited financial statements.

**Development Committee, Beth Dean**

Fundraising training was provided to the Board to work toward leveraging Board relationships moving forward. For the last World TSC Conference there was a sponsorship from the Board which we would like to explore again and will follow up at the March Board Meeting. In 2019 we will host the 45th Anniversary gala and we will be continuing the discussion of locations and honorees.

**Global Relations Committee, David Michaels**

David was happy to share that Andrew Duffy from Canada was present. At their committee meeting, Katie gave an update on Global Alliances and Andrew Duffy gave an update on activities of TS Canada ST. The Global Alliance in Thailand likely receiving their nonprofit status this year and Hungary and next partners in Latin America and India are being discussed. We continue to coordinate with the TSCi website, Global Awareness Day on May 15 and the World TSC Conference where we will work with global partners, speakers and attendees for the 2018 World TSC conference.

**Government Relations, Debora Moritz**

Debora shared that the Patient Focused Drug Development Meeting was a great success. Advocating for CDMRP funding has been a marathon as the community fought against the greatest risks the program has ever faced. The Senate passed damaging language that the House did not. Durbin and blunt co-authored a Dear Colleague letter asking Senators to remove this language and they received 54 signatures, over a majority of Senators. The House letter is circulating and 60 members have signed it. Many aides have said they haven’t seen it and the House is out of session next week so calls are being made and letters being sent to House Representatives. We have to be aware of volunteer fatigue that is created and we need to be conscientious and encourage Board participation. We don’t know yet what things will look like in March or what we will be advocating for at our March on Capitol Hill, March 6-8.

**Outreach Committee, Dena Hook**

Dena reported that the Outreach Committee reviewed progress on goals for 2017 and the 2018 goals. Mary Roberds gave a 2018 World TSC Conference update. The Clinical Ambassador Program was discussed and April Cooper shared plans to restructure to help Community Alliances continue to build community and better sever constituents.

**Other Business**

Jo Anne brought up that there are 13 Co-Directors for new clinics that were not approved for those positions and PAB. The Science and Medical Committee will follow up and approve and submit to the Executive Committee.

Tim announced future board meetings:

* 12/6/17 teleconference at 8pm ET
* 3/6/18 – 3/8/18 in Washington DC
* 6/6/18 teleconference at 8pm ET

**Adjourn**

Motion to adjourn at 6:08pm (*Dean, Lubbers*). The motion passed without dissent.

Respectfully submitted,

Lisa Moss, Senior Director, Donor Relations