**Tuberous Sclerosis Alliance**

**Joint Executive and Finance Committee Meeting Minutes**

**November 3, 2017**

**DRAFT**

**In attendance:**

**Executive Committee Voting Officers:** Tim Dills (Chair), Beth Dean (Vice Chair, by phone), David Fitzmaurice (by phone), Jim Maginn, Rebecca Anhang Price (by phone)

**Executive Committee Member at Large:** Martina Bebin (by phone), Laura Lubbers (by phone)

**Finance Committee Voting Members:** Jim Maginn (Chair), David Michaels (by phone), Darren Miles (by phone)

**Finance Committee Member at Large:** Chris Russell

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

**Call to Order & Chair’s Welcome, Tim Dills, Chair, Board of Directors**

Tim Dills called the meeting to order at 11:02 am PT and confirmed a quorum of voting officers. He congratulated the TS Alliance on the recent announcement of a four-star Charity Navigator rating.

**Approval of the Minutes from the October 13, 2017 Executive Committee Meeting, Rebecca Anhang Price, Secretary**

A motion was made to approve the October 13, 2017 Executive Committee meeting minutes as written (*Maginn/Dean*). *The minutes were approved without dissent.*

**2018 Planning Recap, Beth Dean (incoming chair)**

*Committee Assignments.* The committee reviewed the committee assignments for 2018, described in Attachment B of the agenda. Highlights included:

* The only changes since last review are:
  + The move of David Coit to the Finance Committee and Darren Miles to the Audit Committee; the TS Alliance is seeking a chair of the Audit committee for 2019 as Mike Caggiano will be completing his term on the board in 2018.
  + As Cassie Carroll has agreed to become the Secretary of the Board, David Fitzmaurice will chair the Compensation Committee. Cassie will be a member of the committee, contributing her specific expertise.
* As Rebecca Anhang Price will be focusing on Strategic Planning, new board member Dana Holinka will chair the Outreach Committee, with strong support from Rob Grandia. Peter Crino, Martina Bebin, and Matt Simonian will provide the link from the Outreach Committee to the scientific/medical community. Sara Chieffo and Bonnie Hogue Duffy will provide the link to government relations.
* Sara Chieffo will chair the Government Relations Committee. Both Sara and Committee Member Bonnie Hogue Duffy have extensive experience on the Hill. Several other are community members with experience participating in the March on the Hill. Debora Moritz will still continue to participate in that Committee, share her experience and has agreed to train new March on the Hill participants.
* The Fund Development Committee will be chaired by Tom Gwinn. Brendan Manning was a tremendous asset to this committee in hosting a cultivation event in Boston this past year that was very productive, so he has been asked to participate again, with the plan to host another event in Boston, which is a core location for researchers and funders. The goal is to create a culture on the board in which everyone feels like they’re on the Fund Development Committee.
* Strategic Planning Committee membership was designed to ensure representation by those with longer/shorter experiences with the TS Alliance; by those with children with TSC, those with adult dependents with TSC, and independent adults with TSC; and by those with expertise in each of the core four areas of the strategic plan: research, outreach, organizational capacity, and fundraising.

*2018 Calendar.* Beth reviewed the board and committee meetings scheduled for 2018, described in Attachment C that accompanied the agenda, noting that additional committee meetings will be added over time.

**CEO and CSO Reports, Kari Rosbeck and Steve Roberds**

**2018 Science and Medical Plan, Steve Roberds**

Steve described the focus for 2018, which is growing the Biosample Sample Repository and Preclinical Consortium to achieve critical mass needed for research. All the Science and Medical initiatives work to support one another; for example, biosamples collected can be used for basic research into person-to-person differences in TSC and for discovery of biomarkers to be used in clinical trials.

The Natural History Database has >2100 participants from 18 sites. The Biosample Repository is collecting samples at 7 Natural History Database sites, 5 Rare Disease Clinical Research Network (RDCRN) sites, and 7 PREVeNT trial sites. The Alliance plans to collect cheek swabs at the World TSC Conference, where an anticipated 100-150 individuals with TSC will be present. This has the benefit of both increasing the number of samples and raising visibility of the effort.

Initial targets for the number of samples by 2018 were more aggressive than could be achieved with blood or other types of samples alone; by pursuing cheek swabs, which are less invasive yet useful for genetic studies, the TS Alliance is tracking more closely to target.

The TSC Preclinical Consortium is a collaboration between TS Alliance, industry, and academia, which allows for sharing of data and access to preclinical models. This allows for standardization of models, tests and assays for preclinical drug development, with potential to assess repurposed drugs of interest, analogs with improved safety profiles, and novel compounds and mechanisms of action. This approach engages industry and increases opportunities for clinical trials.

The TS Alliance provides a structure for the work by organizing meetings of working groups, providing project management, and funding providers to do experiments for which data will be shared with all members of the consortium. Strategy and prioritization is set by a steering committee composed of the TS Alliance, academia, industry and a patient advocate. The TS Alliance works with researchers on scientific working groups (currently the functional outcomes group and pathology outcomes group). TS Alliance staff are working to gather a meeting of all partners in early 2018, likely March 1.

All members have access to all validation, phenotypic and reference compound results, including raw data. There are three options for testing compounds nominated by academia or industry. There is a public screening option for reference compounds with results released to the consortium and no IP implication (“Bucket A”), and private screening options for: company compounds with results released to the consortium with an escrow period to protect IP (“Bucket B”), and company compounds with results not released to the consortium and no strings attached with regard to IP (“Bucket C”).

Six companies and three research institutions joined the Consortium, and there are three mouse models currently in use or in validation: one epilepsy model, and two tumor models.

The Consortium is meeting or exceeding 2017 goals, as follows:

* Testing at least 8 compounds in epilepsy and/or tumor models: six are completed or in progress, and two more will start this year.
* Completing neuroinflammation biomarker study in mouse brains: completed.
* Securing at least two additional industry partners or NIH support: 3 additional industry partners have joined, for a total of 6, and two partners from year 1 have renewed for year 2.

Important research findings from the Consortium from 2017 were that MEK inhibitor decreases seizures in a mouse model and relevant targets or markers were identified in brains from the mouse epilepsy model. The groundwork was also laid for more experiments to come, including a cannabidiol experiment in progress, confirmation of the tumor phenotype in TSC2+/- A/J mice bred at Van Andel Institute (licensed from Brigham & Women’s Hospital), and in-progress rapamycin testing in two tumor models.

There are multiple ways to grow the Preclinical Consortium in 2018, including testing more compounds (goal is 12 in 2018, up from 4 in 2016 and 8 in 2017); moving companies forward, since not all companies have tested a compound yet; and growing the number / type of models available for testing. (Note that a TAND model is of interest but that there is a great deal of upfront work required to do so, and it’s not clear how translatable findings would be to humans.) All of these efforts will generate more data for interpretation and sharing within the Consortium.

The budget is directly related to the degree to which the TS Alliance can engage companies in experiments; income on experiments includes all expenses for the experiments plus 10% overhead to the TS Alliance. The effort is highly scalable since costs are covered by companies (plus overhead). From 2017 to 2018, there will be a major shift in payment for experiments from TS Alliance to companies.

For 2018, $675,500 in company-paid experiments expenses were estimated assuming 3 high-cost and 3 lower-cost experiments. The TS Alliance-paid experiments cost estimate of $434,000 was based on the assumption of 2 high-cost experiments and 4 lower-cost experiments, less $100,000. This $100,000 could be pulled out of other parts of the budget by lowering animal supply costs, decreasing the use of the consultant (diverting her time to other activities), or if other projects come in under budget. The staff will watch the expenses very carefully. Although the support costs are mostly fixed, support costs comprise only 12 percent of the Preclinical Consortium budget in 2018, and the research platform is scalable with companies paying the cost of additional experiments.

In October, the Science & Medical Committee voted unanimously to approve 13 new TSC Clinic Co-Directors named below, 2 new TSC Clinic Directors, and 14 new PAB members named below (the 15 names below with the exception of Dr. Kohrman, who is already a PAB member).

New TSC Clinic Co-director Nominees:

1. Stephen Kahler, MD, Little Rock, AR; Specialty: genetics
2. Melissa Crenshaw, MD, St. Petersburg, FL; Specialty: genetics
3. Xia Wang, MD, Tampa, FL; Specialty: genetics
4. Saba Ahmad, MD, Chicago, IL; Specialty: ped neuro/epilepsy
5. L. Richard Feldenberg, MD, St. Louis, MO; Specialty: ped nephrology
6. Bryce Heese, MD, Kansas City, MO; Specialty: genetics
7. Chad Jacobsen, MD, Charlotte, NC; Specialty: ped neuro-oncology
8. David Van Mater, MD, PhD, Durham, NC; Specialty: ped hem-oncology
9. Deborah Rukin Gold, MD, Cleveland, OH; Specialty: ped neuro, neuro-onc
10. Michael Kohrman, MD, Akron, OH; Specialty: ped neuro, epilepsy, sleep
11. Soundarya Gowda, MD, Richmond, VA; Specialty: adult neurology/epilepsy
12. Sarah Kiel, ARNP, Seattle, WA; Specialty: Nurse practitioner experienced in neuro/epilepsy/autism
13. Dawn Siegel, MD, Milwaukee, WI; Specialty: dermatology

New Directors at existing TSC Clinics

1. Dr. Danielle Nolan is replacing Dr. Don Phillips at Beaumont Health System, Royal Oak, MI
2. Dr. Jules Beal is replacing Dr. Fatema Malbari at Montefiore, Bronx, NY

A motion was made to approve the 13 new TSC Clinic Co-directors *(Fitzmaurice/Dean)*. *The motion passed without dissent.*

A motion was made to approve the 2 new TSC Clinic Directors *(Maginn/Fitzmaurice)*. *The motion passed without dissent.*

A motion was made to approve appointment of 14 new PAB members, the 15 names above except Michael Kohrman, who is already a PAB member *(Dean/Maginn)*. *The motion passed without dissent.*

**CEO Report, Kari Rosbeck**

Kari began by sharing excitement about the 4-star Charity Navigator rating, and thanked Rich for his efforts to make that rating possible.

**2018 Organizational Plan: Investment in Community Programs**

In 2009, when the recession hit, the TS Alliance scaled back on staff to support Outreach efforts in favor of research as a priority. Education and Support Services have been separated from Special Events in Community Alliances. There has been some burnout among volunteers. This has resulted in both a need to recruit new volunteers, and a decline in Special Events revenue. In addition, Lundbeck and Novartis industry support will phase out in the near term, so there is a need to re-engage the community.

To do so, it is important to:

* Maximize time spent face to face with the community
* Identify, recruit and cultivate a new generation of volunteers (both Community Alliance and special event leadership)
* Create greater coordination in the local communities
* Increase the capacity for fundraising
* Rebuild and mobilize the grassroots community

Since 2009, the TS Alliance has not used a regional structure. In the proposed reorganization, April Cooper, current Director of Special Events and Corporate Partnerships, would be the Director of Community Programs with three Regional Program Managers, one for the South (13 states, DC, 13 Community Alliances), one for the North (18 states and 12 Community Alliances), and one for the West (19 states and 12 Community Alliances). April will also cover responsibilities for volunteer recognition including the Volunteer and Community Alliance of the Year Nominations, the Keith Hall Distinguished Leadership Award and the annual volunteer appreciation letter/mailing.

Gail Saunders, Associate Director, National Walks and Community Campaigns, would transition to Senior Regional Program Manager for the Southern States and, in addition to the regional responsibilities, she would be responsible for maintaining the Luminate system for the overall walk program and other community campaigns, cross training other Regional Program Managers in the system, coordinate the collection of logistical information for ordering walk shirts, signage and postcards and coordinate with other Regional Program Managers on monthly or quarterly leadership and training calls.

Shelly Meitzler would transition from Community Outreach Manager to Regional Program Manager covering Northern States.

A hire would be made for Regional Program Manager beginning in early 2018 to cover the West Coast and the job search would begin ideally in mid-November. This will be an additional FTE and the salary range would be $50,000-55,000.

Dena Hook, current Vice President Outreach, would become Vice President Support Services and manage all peer to peer volunteer programs under TSC Connect (Clinic Ambassadors, Adult Regional Coordinators, Dependent Adult Transition Resource Coordinators, Junior Ambassadors, Educational Advocates, Education Mentors), supervise the Conference Manager as well as continue as point of support for newly diagnosed, those calling the TS Alliance in need of an advocate and work on educational initiatives. Christen Bell will stay on as the Conference Manager with the Alliance through the World Conference.

A detailed set of metrics have been established for evaluating the performance of the Regional Program Managers against their performance goals. Performance will be based on cultivation and recruitment for open leadership positions, volunteer recruitment, scheduling and attendance at March on the Hill meetings, coordination of social events in the community, identification and reporting of new families to the TS Alliance, fundraising success of Step Forward walks, sponsorship recruitments at the local level, support of community campaigns, and increase in the number of walk teams.

There will be an annual determination of how well the new plan is working, particularly after the first year. In addition, the TS Alliance has built in a “walk back” plan as follows to implement in the case of economic pressure that makes it impossible to maintain the addition of an FTE:

* Set metrics for success of each regional chair position
* Evaluate metrics of each Regional Program Manager to region.
* Survey community to determine if there is engagement or a connection to the manager or where the disconnect is unintentionally causing underperformance.
* Determination made on which Regional Program Manager to release.
* The Community Alliance and state assignments will be redistributed with the Director of Community Programs assuming responsibility for a portion of the West Coast.

Should resources be extremely constrained and/or the new structure deemed ineffective, the following “walk way back” plan is proposed:

* Retain one employee to work with the community on educational events and peer to peer support.
* Add the Director of Community Programs to the Development team as a major gifts officer and have her lead one major special event per year along with a portfolio of donors.

The TS Alliance aims to post a job description for the West Coast Regional Program Manager by November 6, 2017, with resumes due November 17, 15-minute screening interviews for 20 to 25 candidates on November 20-21, one-hour interviews among 10-12 candidates on November 27-29, final interview in DC office on December 5-6, and a start date on January 2, 2018.

The impact on the budget is $60,000 and the total increase to budget is $76,000 inclusive of salary, benefits, and potential incentive compensation.

**World TSC Conference**

Kari reviewed progress to date on major expenses and revenues for the Conference:

* Have already booked 515 of the 1,275 room nights required by the hotel, even though registration has not yet opened.
* Have received sponsorships of $162,500 of the $576,000 budgeted.
  + Rothberg Institute sponsorship committed ($100K)
  + Lundbeck sponsorship committed ($62.5K)
  + Submitted requests or have plans to do so for all potential sponsors in the budget; in addition, submitted requests to 19 board members or members of the community that are not in the budget.
* Have received $3,000 of the $15,000 budgeted for exhibitors.

If there were 100 more participants than anticipated, the TS Alliance would run a $24,316 deficit on the Conference budget; if there were 100 fewer participants, the TS Alliance would run a $65,708 surplus on the Conference budget (although this is not desirable from the perspective of broad participation by the TSC community).

**Taking Board Fundraising to the Next Level**

Building off the great training session at the board meeting in October, the staff is aiming to create a culture of board involvement in major gift fundraising and special events.

The staff is looking to identify three board members who will host cultivation events across the country. Target cities include Boston, New York, Los Angeles or Dallas. The steps are to schedule dates, develop an invite list and mail formal invitations, set the program, and include an ask. In addition, Kari and Lisa are aiming to hold phone or in-person meeting with every board member between December and February. At each meeting, they will discuss fundraising tools/materials, ask the board member to identify at least one new prospect, and develop a plan for cultivation and meeting.

One potentially untapped area of fundraising is working with financial planners / wealth managers, who are sometimes in a position to recommend a charity to their clients.

**Treasurer’s Report, Jim Maginn and Rich Gollub**

**Approval of Meeting Minutes**

A motion was made to approve the August 30, 2017 Finance Committee meeting minutes as written (*Michaels/Miles*). *The minutes were approved without dissent.*

A motion was made to approve the October 12, 2017 Joint Finance/Development Committee meeting minutes as written (*Miles/Michaels*). *The minutes were approved without dissent.*

**Review of Dashboard and Financials for September 30, 2017**

Special Events revenue has a variance because walk revenues are $173K below budget and Other Community Events are running $37K below budget. A grant that had been budgeted for this year did not come through and is not anticipated, so the variance of ~$200K in grants is anticipated to remain through the end of the year.

**With regard to the Balanced Scorecard:**

Accelerating Research targets are being met for the number of compounds tested; overall research spending is $130K under budget, with spending the Biosample Repository and Natural History Database under budget, and the Preclinical Consortium exceeding budget.

Supporting and Empowering Constituents targets are on track;

Educating and Mobilizing to Increase Investment targets will likely not be met; although new fall walks and endurance events are scheduled, we do not expect to meet the annual goal due to walk shortfalls, the loss of the Rock for Riley event and Houston walk due to Hurricane Harvey.

Building and Strengthening the Organization targets will be met for increasing programmatic spending, and close for controlling administrative and fundraising costs and attaining the budgeted functional expense ratio. The ratio has been increasing over the course of the year, and is within the parameters that watchdog agencies look for.

**Statements of Financial Position as of September 30, 2017 and 2016**

There is a significant drop in cash, equivalents and reserve (~$600K), and in pledges receivable (~$500K) since the same date in 2016. The decline in pledges receivable is due to the receipt of the $500K payment from the Engles Family Foundation grant in August.

**Updated Projections for FY17**

Rich presented projections through the end of FY17. Special Events has been a weakness this year. We are hopeful to show improvement in that area in 2018. Fortunately, contract revenue is much higher than originally budgeted; other contributions are also over budget, largely attributable to contributions to the Keith Hall matched memorial fund. Grants are under budget due to the failure of the $200K Pediatric Epilepsy Research Foundation grant to come through. As of September 30, the Alliance has taken $104K from Endowment and received another $100K in October; will wait as late in the year as possible to determine how much of the remainder of the Endowment contribution should be taken, but anticipate that we will need it all.

With regard to program spending categories, the Biosample Repository has not gone as quickly as anticipated, so the projection is $175K less than expected spending. Similarly, the Natural History Database is projected to be $132K under expected. Preclinical Consortium contracts have taken off, so they are projected to be $215.7K more than budgeted, but this is offset by contract revenue from partners.

All in all, projected expenses through FY17 are ~$5.4M, projected revenues are $4.8M, for an overall projected change in net assets of -$600K. The projection is $2.47K in cash and cash reserves as of December 31, 2017.

**Proposed 2018 Budget**

The proposed 2018 budget includes budgeted revenues of $5.69 million, including $885K (18.4%) more than projected 2017 revenues. The World TSC Conference accounts for ~85% of this increase ($754K). Budgeted expenses are $6.16 million (14.4% more than projected 2017 expenses. The World TSC Conference accounts for ~94% of the increase. There is a budgeted net deficit of $0.47M due to spending on research funded by the Engles Family Foundation grant received in 2016.

The primary revenue changes from 2017 to 2018 are:

* ~$591K in sponsorships, $155K in registration fees, and $8K in other revenue from the World TSC Conference
* $388K more in contract income from Preclinical Research Consortium
* $190K less in appeal donations
* $120 less in grant revenue

The primary expense changes from 2017 to 2018 are:

* $733K more in costs related to World TSC Conference
* $207K more in staff expenses (covering the new position on the staff due to restructuring plus 2% increase for other staff and increase in health insurance costs)
* $179K more in the Preclinical Research Consortium (associated with corresponding revenues)
* $113K less in meetings and conferences (excluding the World TSC Conference)
* $55K less in travel (excluding the World TSC Conference)

2018 is a bigger pie than 2017, with sponsorships much larger due to World TSC Conference, and contracts up from 17% to 21% due to the Preclinical Consortium.

Charity Navigator’s recent rating of 4 stars was partially based on the functional expense ratio improving from 2015 to 2016; program expenses in 2016 composed 76.3% of expenses. This is projected to rise to 76.9% in 2017, and is budgeted to rise to 80.5% in 2018.

Projected cash and cash reserves as of 12/31/2018 are anticipated to be lower than on 12/31/2017.

The staff will plan to look at projected net assets and the breakdown of restricted and unrestricted every quarter. Under new GAAP guidance, these categories no longer be referred to as temporarily or permanently restricted or unrestricted net assets, but rather as “donor restricted net assets” and “net assets without donor restrictions.”

A motion was made for the Finance Committee to approve the FY2018 budget as presented (*Michaels/Miles*). *The budget was approved without dissent.*

A motion was made for the Executive Committee to approve the FY2018 budget as presented (*Fitzmaurice/Maginn*). *The budget was approved without dissent.*

**Update from Governance Committee, David Fitzmaurice**

David reminded the group of the decision to move forward with maintaining the TS Alliance as a membership organization, with little investment in staff time to promote membership.

In response to the October 2017 vote on changes to the bylaws related to membership, Kari received an unsolicited request from Will Cooper regarding how to become a Lifetime Member.

David reminded the committee of the historical perspective on membership. Lifetime Membership began in 1995 with what was considered substantial dues of $1,000. Currently, there are 273 Lifetime Members. 28 made a $1,000 donation indicating the wish to be a Lifetime Member. 27 made a $1,000 general donation with Lifetime Membership granted retroactively. 34 made >$1,000 donation. 154 people have Honorary or Complimentary Lifetime Membership. 30 remaining lifetime members have no valid addresses on file. Membership stopped being a fundraising vehicle in the late 2000s as the recession hit. The highest “price” for membership was for a $5,000 Gold Level membership when the TS Alliance stopped collecting membership dues in 2016.

Although the TS Alliance will not seek out Lifetime Members, there needs to be a policy in place when someone approaches the organization with the request to become a Lifetime Member. The Governance Committee and staff have proposed a Lifetime Membership fee of $25K, as this is considered a substantial gift, and is the threshold for establishment of a named fund.

Questions include:

* Do we offer Lifetime Membership? If so, at what rate?
* Do we honor Will Cooper’s contribution to the organization with an honorary Lifetime Membership?
* Do we “undesignate” those without valid addresses as Lifetime Members?

Legal Counsel has indicated that we “can designate any member as a Lifetime Member and does not limit TS Alliance as to how to do so, when, or for what amount in dues.”

However, upon discussion, the Executive Committee agreed that the TS Alliance has made a strategic decision to move away from membership, and that therefore, accomplishments and contributions to the TS Alliance should be honored in a different way. Should individuals approach the organization about becoming Lifetime Members, these individuals should be instructed that there is no longer a Lifetime Membership program. Instead, the staff will consider how to honor individuals who have made lifetime contributions to the TS Alliance with a special designation, such as a “hall of fame,” “ring of supporters” or “champions.” Such a designation may or may not be tied to donations depending on the circumstance.

The Committee agreed that there is no need to address the issue of members without valid addresses at this time, since there are few of them and there has not historically been an issue of getting a quorum for votes (event when including members without addresses in the denominator).

**Outreach Committee Update**

November 4 is the transition workshop in San Diego at the tail end of the national ARC National Conference. Twenty-four people attended the transition workshop event in NY, and it was clear that there is a significant unmet need for the information that these workshops provide. Substantial planning is required for transition, regardless of whether the child is dependent or independent; needs include financial planning, guardianship, medical transitions (e.g., independence in taking medication). Although transition planning is often recommended to begin at age 13, many wait to address them until age 18. The workshops are the fruition of partnerships developed over the last few years with the Child Neurology Foundation (medical transition), ARC (employment, housing, waivers), and Mass Mutual (financial planning). Dena also gives a session on IEPs, and how to transition from school to community and what should be included for those purposes (e.g., social skills, living skills).

**Strategic Planning Committee Update**

The Strategic Planning Committee has been established to incorporate the perspectives of adults with TSC, parents of young children with TSC, parents of dependent adults, clinicians and scientists, those with expertise in organization building and fundraising, and those with less and more experience with the TS Alliance. The major milestones of the strategic planning process are as follows:

* Develop, administer and analyze data from a constituent survey (fall 201 – April 2018), with results presentation at the World TSC Conference in July 2018
* Gain input from board and community leaders (October 2017 Board meeting “bucket” exercise, March 2018 Board meeting with Community Alliance Chairs)
* Integration of these inputs by Strategic Planning Committee, with the following steps planned:
* Letter to committee welcoming them and sending copy of book on January 1
* Meetings with goals to:
  + Review mission and vision statement, the four categories of the OGSM: January/February 2018
  + 1 to 2 meetings for each of the four categories:
    - Accelerating Research: April
    - Support & Empower Constituents: May
    - Educate & Mobilize to Increase Investment: June
    - Build and Strengthen Organization: July/August
* Development of Theory of Change indicators by staff (staff retreat in August 2018)
* Presentation and discussion of draft strategic plan to Board (October 2018 board meeting)
* Presentation of final strategic plan for a vote (December 2018 Board meeting; can move to March 2019 if needed)

**Government Relations Committee Update**

Kari gave the update on the National Defense Authorization Act (NDAA), which was drafted to contain provisions that only allow CDMRP to fund medical research that is for Active War fighters (i.e., not veterans, retirees, military spouses, or children of military members); would require medical research grant applicants to meet the same accounting and price standards that the Department of Defense requires for multi-billion dollar weapons development contracts; would have government owning the IP for researchers; and would require the Defense Contract Audit Agency (DCAA) to conduct audits on every grant recipient. In current Conference Committee negotiations, TS Alliance staff have learned that all of these provisions are being removed with the exception of the certification that the research will benefit Active War Fighters. It is not clear whether the Active War Fighter definition would be construed broadly to include CDMRP research.

The tax reform bill has many potential implications for the TSC community. For example, the bill removes tax breaks for pharmaceutical companies to invest in orphan drug, thereby removing the incentives of drug companies to develop drugs for rare disease like TSC.

Emails from the TS Alliance regarding government relations help to keep people informed, but may also raise anxiety given concerns about insurance coverage and affordability of health care.

**Action Items and Next Steps**

* Post job description for West Coast
* Respond to Will Cooper re: request for Lifetime Membership
* Note that the final meetings for 2017 are as follows:
  + November 29, 8 p.m.:  Joint Finance and Executive Committee Meeting – has been cancelled since the budget was already approved.
  + December 6, 8 p.m.:  Board Meeting Teleconference
  + December 20, 2 p.m.:  Finance Committee Meeting (can be cancelled if the Treasurer feels there is not adequate business to conduct)

**Adjourn**

There being no further business, a motion was made to adjourn the meeting *(Maginn/Fitzmaurice). The motion passed without dissent.* Meeting adjourned at 3:00 pm PT.

Respectfully submitted,

Rebecca Anhang Price, Secretary