

**TSC Alliance
Outreach Committee Meeting Minutes
March 3, 2022
DRAFT**

In Attendance

Board Committee Members (voting): Derek Bauer, Margaret Cox, Sara Chieffo, Rob Grandia, Diane McSwain

Board Committee Members (non-voting): Jessica Krefting

Non-Board Committee Members: Jonathan Goldstein, Lauren Schillinger

Guests: Shalonda Alexander, Melissa Bartlett, Frank Cenna, Jocelyn Cenna, Danielle Clark, Lara Falcon, Jackie Grenia, Shannon Grandia, Tammy Kouns, Iris Mustich, Daniel Price, Phil Tallman

TSC Alliance Staff: Ryan Beebe, April Cooper, Landon Cox, Zoë Fuchs, Jaye Isham, Dan Klein, Shelly Meitzler, Lisa Moss, Jo Anne Nakagawa, Ashley Pounders, Mary Roberds, Kari Rosbeck, Gabrielle Rushing, Gail Saunders, Anne Wolfe

Welcome

Rob Grandia (standing in for Dana Holinka) welcomed everyone, confirmed a quorum, and called the meeting to order at 8:30am eastern.

Approval of Outreach Committee Meeting Minutes from October 8th, 2021 and January 24th, 2022

Margaret Cox moved to approve the October 8th, 2021, and January 24th, 2022, Outreach Committee meeting minutes as written. *Derek Bauer* seconded the motion and the October 8th, 2021, and January 24th, 2022, minutes were approved without dissent.

Review of 2021 Results & Outcomes

April reviewed progress on Outreach Goals for FY2021 and outcomes through December 31st, 2021. Full details and outcomes measures were included in the pre-meeting materials provided to the committee. The TSC Navigator was launched officially in October 2021. April requested feedback on increasing replies for the “TSC Clinic Patient & Family Experience of Care Survey”. Work continues on advancing EDI outreach, engagement and programming.

2022 World Conference Updates

Shelly provided updated statistics on World Conference registration as of February 28th. At the time, there were 96 registered attendees, including 66 in-person attendees, 6 virtual attendees, 16 day campers and 8 dinner-only attendees. The hotel block reflected 246 attendee room nights booked and 108 staff room nights. The scholarship deadline for applications was March 1st and 89 total applications were submitted; all applicants were notified of their acceptance status on March 15th.

Shelly provided updates on the World Conference planning process and asked for feedback on evening activities and potential themed events. Feedback on the grandparent’s meetup was that it worked well as an informal gathering and doesn’t need a more formal program or structure. The group recommended *Encanto* as a great movie potential for one evening. Karaoke was also suggested as a possible evening activity and received a positive response.

On themes for the opening dinner, most felt that it was better to keep things informal for the opening night to allow everyone to acclimate back to being in person. However, everyone agreed that there should be more details on the programming and logistics, especially since the hotel is large and daunting to navigate, especially for newcomers. A 'blue' theme was suggested, but Saturday night is already our 'blue' night.

Additional suggestions included bracelets or other items to indicate comfort level with interaction with others (e.g. green for hugging, yellow for handshakes, red for no touching, etc.). Derek Bauer asked about engagement on social media and plans to share what is happening on site. Further details will be provided as we approach the event, including utilizing the conference app, as well as sharing to outside channels to raise awareness and share the celebration onsite.

Next steps included speaker travel coordination, working group calls for speakers, next Dallas site visit, April 13-15. The staff will be meeting with Adult Regional Coordinators and Future Leaders to discuss what they would like to see for meetups or evening activities specific to adults and young adults. Shelly will also inquire about potential screening of *Encanto* for families as an evening event.

ED&I Outreach 2022 Goals -Review and Brainstorming

Anne presented on progress to date on ED&I goals on behalf of the EDI Task Force. Anne is now acting as the Staff Lead, taking over for Julie Scroggins, and is partnered with the Board Lead, Laura Marks. Progress has been made along three workstreams – Internal Processes, Training & Governance, Outreach and Communications. Completed projects include building the EDI Task Force and working groups, creating a multicultural gathering for the World Conference, translating the "TSC Clinic Patient & Family Experience of Care Survey" (now available in Spanish on the TSC Alliance website) and expanding internal training. Ongoing initiatives include improving data collection around demographics, expanding collaborations with community-based organizations and broader rare disease EDI initiatives, expanding Spanish-language resources and growing outreach to underserved and historically excluded communities.

Anne shared next steps and recommendations around community training and the importance of self-awareness and intentionality in approaching all of these conversations and goals. Trust is more easily broken than built and it's important to meet communities where they are at. Shannon also spoken to the value of showing up at other community events, rather than just asking underserved communities to show up when they don't know us.

There was a robust discussion around how to advance EDI within the TSC community, especially as related to Community Leader training. Lauren and Jonathan both inquired about how we were approaching training. Diane offered that a self-awareness or reflection exercise could be a good starting point for individual leaders around bias and privilege; Margaret also supported looking into that idea. Anne suggested that unconscious bias training was a good place to start, and Iris endorsed.

Diane and Kari added that there have been many gains in accessibility and inclusivity for the TSC community, especially in greater support for adults impacted by TSC, which is worth celebrating while also recognizing growth still to come. It is also important to note that we can build from the inclusion we have fostered for disabled individuals and community members. Lara Falcon added that UCB is looking at these same questions and have begun outreach to non-traditional partners, such as faith-based organizations, which can be trusted community partners. Danielle also noted that it is important in translated or culturally competent materials to be aware of literacy and health literacy levels in different communities.

There being no other business, *Derek Bauer* moved to adjourn the meeting and *Margaret Cox* seconded the motion. The meeting was adjourned at 10:01am.

Respectively submitted,

Anne Wolfe
Senior Community Programs Manager