

**TSC Alliance
Outreach Committee Meeting Minutes
August 9, 2022
DRAFT**

In Attendance

Board Committee Members (voting): Dana Holinka (Chair), Tanjala Gipson, Rob Grandia, Lesley Holmes

Non-Board Committee Members: Jonathan Goldstein, Noor Panjwani, Lauren Schillinger

TSC Alliance Staff: April Cooper, Carly Kaye, Shelly Meitzler, Ashley Pounders, Kari Rosbeck, Gail Saunders, Anne Wolfe

Welcome and Introductions

Dana Holinka, Outreach Committee Chair, welcomed everyone to the meeting at 6:03 p.m. MT (8:03 p.m. ET). A quorum of voting members was not present.

April Cooper was invited to introduce the newest non-Board Committee Member, Noor Panjwani. Given that there is some additional time in the agenda, Dana invited each attendee to introduce themselves briefly. Introductions concluded at 8:14 p.m. ET and Dana returned to the main agenda.

Approval of Outreach Committee Meeting Minutes from March 3, 2022

Without a quorum of voting members, March Outreach Committee Meeting Minutes will be held for approval until the October 23, 2022 Board Meeting.

Review of 2022 Outreach Goals - Progress Report

April shared a presentation which reviewed progress on all 2022 Outreach Goals through June 30, 2022.

April shared updated statistics on the utilization of the TSC Navigator and associated support services which are all on track in relation to targeted reach and engagement.

There was a discussion surrounding the progress to date on the TSC Clinic Patient & Family Experience Care Survey and why it is always a challenge to reach targeted completion rates. There was a conversation on how the survey is disseminated and what barriers there may be in gathering feedback. Jonathan noted that he has never received one and Ashley noted that clinics tend to distribute them via different methods and channels. A recurring challenge has been that while surveys are anonymous, many clinics can still identify a patient or family from what feedback is received, which leads to hesitation in sharing their feedback.

Regarding peer-to-peer support numbers, April reminds the group that this goal was reduced/revised in 2021 and stayed at a lower level for 2022 due to impacts of the pandemic on these measures. For example, IEP meetings have been less requested, although they are now starting to see an uptick. Additionally, clinic ambassador recruitment has been a challenge and is behind, primarily due to restrictions within clinics and hospitals. It was decided to circle back on the topic in the discussion on 2023 goals, as there are some proposed new tactics to address these issues.

April also provided an update on gaining feedback from community leaders and members of the volunteer support network. The Community Alliance Leader Survey was converted into one-on-one feedback sessions to gain insights from the community about how we can better support them and

foster a sustainable volunteer network. The ED&I Task Force continues work on further defining and prioritizing goals and initiatives. Two multicultural gatherings were held this year (virtually and at the World Conference) and the first Spanish-language webinar is confirmed for August 30; the new Spanish-language page on the website was also launched at the World Conference. The first Volunteer Training module (onboarding) will be live in TSC Academy by the end of 2022; goal is to create a resource center as well that replicates part of BoardLink.

On the final goal of a successful World Conference, while attendance was slightly below the goal, it was really a great event and with so many complicating factors (COVID, inflation, travel challenges, etc.) the event was clearly a success and well-received by the community. Appreciation was expressed by all for the work that was done to achieve this, particularly by Shelly.

Review of 2023 Draft Outreach Goals

Following updates on FY2022 goals and progress, April also reviewed the FY2023 proposed Outreach Goals.

Dana asked how we are continuing to promote and sustain engagement with and utilization of the TSC Navigator, as well as what plans exist for growth and further development. Ashley shared some next steps in content development, including the updated Navigation Guides (formerly Life Stages and Personal Journals), as well as continuing to add and update new information and resources for additional stakeholders (e.g. health care providers, nurses, etc.). Ashley asked for feedback on ways to further measure impact, as that can be hard to quantify beyond views. Lauren suggested another webinar on how to navigate the TSC Navigator, as well as educating volunteer leaders on how they can share those resources; Rob and Dana agreed. Dana also suggested adding a survey as well. Additional suggestions included a 'welcome to the TSC Navigator' landing page and having a video Q&A on social media that could be shared or pinned to pages. Feedback will be shared with the Communications Department as well since this is both a Communications and Outreach goal.

Committee members then discussed if there was an opportunity to combine the Constituent Survey and the TSC Clinic Patient & Family Experience Care Survey. Given that they have distinct purposes, Kari recommends that they are not combined; however, staff will evaluate additional opportunities to better disseminate and reach target audiences with the Clinic survey, in particular. Lauren expressed that there is sometimes confusion between the TSC Alliance survey at clinics and the clinics' own surveys; she recommended that we more clearly explain the importance (the 'why') of completing the survey and identify ways to incentivize families to complete it. Ashley noted that the team will also look at ways to further anonymize/de-identify survey feedback to ensure that families feel comfortable sharing their feedback candidly.

The group also reviewed 2023 plans for volunteer training and support, including implementing a new training module/course (Community Leader Basics – inclusive of unconscious bias, peer-to-peer support, and crisis mgmt. training) with 100% completion by YE 2023. April also shared additional information on plans to better network and connect volunteer leaders within their roles (e.g. connecting all chairs or EPs for shared calls and networking). There is also a lot of interest in expanding support groups and activities for teens and young adults.

Regarding the Clinic Ambassador program, Shelly shared some proposed updates to make the model more flexible, since the current model doesn't work with many clinics, especially since the pandemic changed rules and standards. While the goal would be to open up some opportunities for Clinic Ambassadors virtually, Kari recommends emphasizing onsite where possible to stay true to the mission of the role.

The Community Programs team also shared plans to host 3-4 regional conferences in 2023. Preliminary locations include Washington DC (coinciding with the International Research Conference), Seattle (Pacific Northwest), Denver (or Utah), and potentially Chicago; the goal is to have the conferences spread out across geography and time zones. Conferences would likely be in-person only; virtual option could be considered if budget allows, but we are likely limited.

Since there was not a quorum present, approval of the FY2023 Outreach Committee goals will be tabled until the October Board meeting.

Adjournment

There being no other business, *Dana Holinka* moved to adjourn the meeting and *Rob Grandia* seconded the motion. The meeting was adjourned at 9:06pm ET/7:06pm MT.

Respectively submitted,
Anne Wolfe
Senior Manager, Community Programs

Outreach Progress Overview

FY 2022

1. Implement website-based TSC Navigator to help TSC individuals/caregivers to navigate access to FDA-approved therapies and other support services.
 - a. Reach 1,000 views on the TSC Navigator page
 - 1,327 unique views through June 30, 2022
 - b. Provide support for 500+ encounters with the TSC community whether newly diagnosed, those in need of appropriate support or assistance in clinical care
 - 330 unique encounters as of June 30
 - c. Facilitate a minimum of 50 of the 500 encounters for medication access issues
 - Facilitated 23 medication access issues through June 30, 2022.
2. Distribute “TSC Clinic Patient & Family Experience Care Survey” to individuals/caregivers through TSC Alliance social media channels and e-blasts throughout 2022 with a year-end response rate from English-speaking respondents at each TSC Clinic/TSC Center of Excellence receiving at least 10 completed surveys from clinics with fewer than 100 patients, or 10% if 100 or more.
 - a. 60 surveys were received through April 30.
3. Increase peer-to-peer support annually by 10% over 2021 and motivate a new generation of volunteers/advocates for the TSC Alliance by adding 100 new volunteers to the TSC Connect Network, focusing on the underserved and underrepresented.
 - a. provide 600* volunteer training hours to the TS Alliance Leadership in 2021
 - 482 training hours provided through June 30
 - b. grow the number of TSC Clinic Ambassadors to 22 serving 22 TSC Clinics
 - 15 TSC Clinic Ambassadors serving 14 TSC Clinics as of June 30
 - c. enhance and expand resources available at the state level to address education, and transition of dependent adults through DATRC (dependent adult transition resource coordinator program)and grow to 33 in 2022
 - 29 DATRC as of June 30
 - d. support families in need of educational advocacy by attending or consulting on 100 school meetings in 2022
 - 23 school meetings attended through June 30
 - e. This goal was revised (reduced goal) last year due to factors related to the pandemic and it was decided to stay with that level for 2022 as it is much more realistic.
 - f. Clinic ambassador recruitment has been a challenge and is behind, primarily due to restrictions within clinics and hospitals.
4. Utilize Community Alliance leaders and TSC Clinic Ambassadors to help identify and serve the underrepresented areas and populations where we can provide information about TSC and better support those affected.
 - a. collect constituent demographic data utilizing the CA Leader Survey with a 75% response rate – adding data fields to information requests, webinar registrations and world conference registrations – to identify the underrepresented populations in our community. Fields were added to the World Conference and Webinar registrations.
 - The CA Leader Survey was converted into one-on-one feedback sessions.
 - Feedback to date includes many positive things, but also numerous requests for more resources and better connectivity between leaders in parallel roles.
 - Additionally, leaders want to ensure that opportunities are accessible for those with different abilities, time, skills, etc.
 - b. Develop and begin to implement intentional strategies to reach out to the underrepresented populations. ED&I Task Force is regrouping and redefining

overarching goals. The Outreach Committee will work to implement recommendations with target completion dates.

- Multicultural gatherings held pre-conference (virtually) and in-person at the World Conference
 - Have launched new Spanish-language website and additional translated resources; plan to host first virtual Spanish-language webinar on August 30.
 - Continue to build list of Spanish-speaking and multicultural community members as target audience for continued outreach and activities.
- c. Develop one new training module/course (Community Leaders Onboarding) for TSC Academy and ensure 100% of new sponsored TSC community leaders advocates participating in the 2022 March on the Hill complete Advocacy Training prior to attending the event in person
- 100% of new participants completed Advocacy Training ahead of the 2022 Virtual March on the Hill
 - A basic onboarding module for Community Alliance leaders will be developed prior to the end of 2022.
 - First Volunteer Training module will be live in TSC Academy by the end of 2022; goal is to create a resource center as well that replicates part of BoardLink.
5. Host a successful 2022 World TSC Conference with 1,000 attendees either in person or via live stream to provide adults and families affected by TSC information and social support
- 938* registered participants
 - 458 in-person
 - 121-day campers
 - 154 event staff/speakers
 - 147 virtual attendees
 - 34 dinners only
 - *16 virtual nurse attendees

FY2023 – Proposed Outreach Committee Goals

1. Work with the Office of the President to incorporate the voice of the community as we develop a new strategic plan including fielding a constituent survey in early 2023 and holding a workshop at the 2023 Volunteer Leadership Summit in March.
 - Determine the met and unmet needs of constituents, as well as assess the effectiveness of programs established by the TSC Alliance in order to ensure that the organization continues to live up to its mission.
 - Provide key relevant findings from the constituent survey to each of the TSC Alliance Committees and Sub-Committees that will help develop strategies moving forward.
2. Distribute the “TSC Clinic Patient & Family Experience Care Survey” to individuals/caregivers through TSC Alliance social media channels and e-blasts throughout 2023 with a year-end response rate from English-speaking respondents at each TSC Clinic/TSC Center of Excellence receiving at least 10 completed surveys from clinics with fewer than 100 patients, or 10% if 100 or more. – (educate the TSC Clinics and TSC families about receiving their anonymous feedback – changing how we deliver the information to the TSC Clinics – can we incorporate anything into the constituent survey)
2. Strengthen the Community Alliance structure and motivate a new generation of volunteers / advocates for the TSC Alliance
 - Implement a new training module/course (Community Leader Basics – inclusive of unconscious bias, peer-to-peer support, and crisis mgmt. training) with 100% completion by YE 2023.
 - Provide 600 volunteer training hours to the TSC Alliance Leadership in 2023.
 - Ensure 100% of new sponsored TSC community leaders advocates participating in the 2023 March on the Hill complete Advocacy Training prior to attending the event in person.
3. Increase peer-to-peer support annually by 10% over 2022 by inspiring volunteers/advocates to collaborate and enhance services provided on behalf of the TSC Alliance by adding 100 new volunteers to the TSC Connect Network, focusing on the underserved and underrepresented.
 - Provide Quarterly Collaboration and Support opportunities for each peer-to-peer volunteer group (TSC Clinic Ambassadors, EPMs, DATRC (or SRC), Young TSC Adults with monthly TSC Adult calls with the ARC)
 - Launch a TSC Alliance Clinic Ambassador Program to grow from 15 serving 14 TSC Clinics to 30 serving of 30 by December 31, 2023.
 - Enhance and expand resources available at the state level to address all resources including education, transition, and dependent adults through the DATRC (Dependent Adult Transition Resource Coordinator) program with the creation of the State Resource Coordinator (SRC) growing those serving to 50 in 2023.
 - Support families in need of educational advocacy by attending or consulting on 150 school meetings in 2023 – including 75 school meetings, 50 IEP consultations, and 25 TSC 101 trainings.
4. Host four (4) Regional Conferences (in each time zone)
 - Washington DC (EST) Sept 2023 to coincide with the TSC Research Conference
 - PNW (Seattle) (PST)
 - Denver / Utah (MST)
 - Chicago (CST) – tentative