



Boston Regional Conference Agenda

Saturday, May 3, 2025

8:00 – 8:30 am

Check-In/Registration

8:30 – 9:00 am

Welcome and Opening Session:

A brief overview of the conference, setting expectations for the day's learning with information on ways to participate in Anya's Accelerator.

Speakers: Kari Luther Rosbeck, President & CEO; Dean Aguiar, PhD, Vice President, Translational Research, TSC Alliance

9:00- 10:15 am

Track 1: Strategies for Managing Behaviors in TAND

An overview of TSC–Associated Neuropsychiatric Disorders (TAND) and how to effectively navigate the system to access resources and support; medical and non–medical interventions available; when and how to use behavioral interventions; and practical tools and tips.

Moderator: [Elizabeth Thiele, MD, PhD](#)

Speaker: [Peter Davis, MD](#)

Track 2: Skin Manifestations and Treatment Options

Clinical consensus guidelines and treatment options (including surgical removal and FDA–approved medications) for skin manifestations and how clinical presentations vary across different skin tones.

Moderator: Shelly Meitzler, Director, Outreach & Support, TSC Alliance

Speaker: TBD

10:15 – 10:30 am	BREAK
10:30 am – 12 pm	<p>Track 1: Seizure Types and Treatments <i>How TSC impacts the brain, seizure types common in individuals and an overview of rescue medication.</i></p> <p>Moderator: Mustafa Sahin, MD, PhD Speaker: Jurriaan Peters, MD, PhD</p> <p>Track 2: Brain Manifestations in Adults with TSC <i>How TSC impacts the brain, including seizure types in adults, and a focus on TSC-Associated Neuropsychiatric Disorders (TAND) and the impact on quality of life.</i></p> <p>Moderator: Sam Metzgar, Scientific Project Manager, TSC Alliance Speaker: Elizabeth Thiele, MD, PhD</p>
12 – 12:45 pm	LUNCH
12:45 – 2 pm	<p>Track 1: Caregiver Mental Health and Well-Being <i>Resources and information to ensure caregiver mental health and well-being and to empower caregivers to advocate for themselves.</i></p> <p>Moderator: Mustafa Sahin, MD, PhD Speaker: Kitty Petty, MA, MEd, LMCH</p> <p>Track 2: Kidney Tumors, Cysts and Treatment Options <i>Current approaches to caring for people with kidney manifestations, including medical and surgical interventions.</i></p> <p>Moderator: Kari Luther Rosbeck, President & CEO, TSC Alliance Speakers: Elahna Paul, MD, PhD , Christoper P Dall, MD</p>
2 – 2:15 pm	BREAK
2:15-3:45 pm	<p>General Session: Research Updates and Upcoming Clinical Trials <i>The current state of TSC research, Quality Improvement Initiatives and more.</i></p> <p>Moderator: Dean Aguiar, PhD, Vice President, Translational Research, TSC Alliance Speakers: Nicola Alesi, MD, PhD Brendan Manning, PhD Panelists: Mustafa Sahin, MD, PhD, Elizabeth Thiele, MD, PhD</p>
3:45 – 4 pm	BREAK
4 – 5:30 pm	General Session: Understanding the Genetics of TSC and Family Planning

an overview of the genetics of TSC and family planning options: Maternal Fetal Medicine experts will cover how to navigate reproductive and perinatal health decisions through postpartum, current gaps in consensus guidelines for care, diagnosing TSC in utero and what's on the horizon. Additional specialists will provide health considerations for women with TSC and/or LAM when making reproductive decisions.

Moderator: Dean Aguiar, PhD, Vice President, Translational Research, TSC Alliance

Speakers: [David Kwiatkowski, MD, PhD](#), Maternal Fetal Medicine, TBD

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