



**Northern California Regional Conference Agenda**  
 November 16, 2024 | Hyatt Centric Mountain View, 409 San Antonio Rd  
 Mountain View, CA 94040  
 Draft Agenda – Updated October 14, 2024

8:30 – 9:30 am	<b>Check-In/Registration</b>
9:30 – 10:45 am	<p><b>Welcome and Opening General Session: Research Updates and Upcoming Clinical Trials</b>  <i>An overview of the day’s sessions and the current state of TSC research, including Anya’s Accelerator, Quality Improvement Initiatives and more.</i></p> <p>Speakers:</p> <ul style="list-style-type: none"> <li>• Kari Rosbeck, President &amp; CEO, TSC Alliance</li> <li>• Dean J. Aguiar, PhD, Vice President, Translational Research, TSC Alliance</li> </ul>
10:45 – 11 am	<b>BREAK</b>
11 am – 12 pm	<p><b>Track 1: Pediatric– Seizure Types and Treatments</b>  <i>How TSC impacts the brain, seizure types common in infants and children affected, and an overview of rescue medication.</i></p> <p>Moderator: Shelly Meitzler, Director, Community Support &amp; Outreach, TSC Alliance</p> <p>Speaker: Brenda E. Porter, MD, PhD, Director, Northern California TSC Clinic, Lucile Packard Children’s Hospital</p> <p><b>Track 2: Adult – Seizure Types and Treatments and Adult Seizure Action Plans</b>  <i>How TSC impacts the brain, seizure types common in adults affected and using rescue medications.</i></p> <p>Moderator: Elizabeth Skufca, Community Programs Manager, TSC Alliance</p> <p>Speaker: Scheherazade Le, MD, Co-Director, Stanford Hospital &amp; Clinic, Northern California TSC Clinic</p>
12 – 1 pm	<b>LUNCH</b>
1 – 2 pm	<b>Track 1: Pediatric – Caregiver Mental Health and Well-Being</b>

*Resources and information to ensure caregiver mental health and well-being and empower caregivers to advocate for themselves.*

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

**Track 2: Adult – Kidney Tumors, Cysts and Treatment Options**

*Current approaches to caring for patients with kidney symptoms, including medical and surgical interventions.*

Moderator: Elizabeth Skufca, Community Programs Manager, TSC Alliance

Speaker: Seolhyun Lee, MD, Clinical Assistant Professor, Medicine – Nephrology Stanford University Medicine

2 – 2:15 pm

**BREAK**

2:15 – 3:15 pm

**Track 1: Pediatric – 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: Shelly Meitzler, Director, Community Support and Outreach, TSC Alliance

Speaker: Janani Venugopalakrishnan, MD, Clinical Associate Professor, Psychiatry, Stanford University Medicine

**Track 2: Adult – 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: Elizabeth Skufca, Community Programs Manager, TSC Alliance

Speaker: Joyce Teng, MD, PhD, Professor of Dermatology, Stanford University Medicine

3:15 – 3:30 pm

**BREAK**

3:30 – 4:30 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 J. Aguiar, PhD, Vice President, Translational Research, TSC Alliance

Speakers:

- Lara A. Friel, MD, PhD, Maternal Fetal Medicine Specialist, UTHealth; Associate Professor, University of Texas Health Science Center at Houston/The McGovern Medical School; Co-Chair; TSC Alliance Reproductive and Perinatal Initiative
- Lusine Aghajanova, MD, PhD, Clinical Associate Professor, Obstetrics & Gynecology - Reproductive Endocrinology & Infertility, Stanford University Medicine

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