



## TSC Regional Conference Agenda

### November 8, 2025

- 8:00-8:30 am **Check-In/Registration | Centennial AB**
- 8:30-9:30 am **Welcome and Opening General Session: Research Updates and Upcoming Clinical Trials | Centennial AB**  
*A brief overview of the conference, setting expectations for the day's learning followed by an update on the current state of TSC research, including Anya's Accelerator (a TAND initiative) and pipeline of new treatments for TSC.*
- Speakers: **Kari Luther Rosbeck**, President & CEO, TSC Alliance; **Dean Aguiar, PhD**, Vice President, Translational Research, TSC Alliance; **Shafali Jeste, MD**, Professor and Mattel Executive Endowed Chair of Pediatrics, David Geffen School of Medicine, Executive Medical Director, Pediatrics, UCLA Health System; **Raj Rajaraman, MD, MS**, Epileptologist, Associate Professor, Director of the UCLA Tuberous Sclerosis Center of Excellence UCLA Mattel Children's Hospital David Geffen School of Medicine
- 9:30-9:45 am **BREAK | Centennial AB**
- 9:45-10:45 am **Understanding the Genetics of TSC | Centennial AB**  
*This session offers an overview of the genetic causes of TSC, focusing on mutations in the TSC1 and TSC2 genes. Learn how these mutations affect the body, how TSC is inherited, and the role of genetic testing in diagnosis and treatment planning.*
- Moderator: **Shelly Meitzler**, Director, Outreach & Support, TSC Alliance  
Speaker: **Julian A. Martinez, MD, PhD**, Assistant Professor, Pediatrics, Pediatric Genetics, Medical Genetics Clinic, UCLA School of Medicine
- 10:45-11:45 am **Track 1: Caregiver Mental Health and Well-Being | Centennial AB**  
*Learn practical ways to support your mental health, find helpful resources, and advocate for your needs while caring for an individual with TSC.*
- Moderator: **Elizabeth Skufca**, Community Programs Manager, TSC Alliance  
Speaker: **Jessica Appell, MSW**, Clinical Social Worker with the UCLA Care Coordination Pediatric team; **Sabrina Mohamed Rafi, PsyD**, Clinical Psychology Postdoctoral Fellow with the UCLA Pediatric Epilepsy Center and Department of Psychiatry.

**Track 2: Skin Manifestations and Treatment Options | Laureate Classroom**  
*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: **Kari Luther Rosbeck**, President & CEO, TSC Alliance

Speaker: **Ronald W. Cotliar, MD**, Clinical Professor of Dermatology and Pediatrics, UCLA, Attending Pediatrics Dermatologist, UCLA Mattel Children's Hospital

11:45 am-12:45 pm **LUNCH | Centennial AB**

12:45- 2:00 pm **Kidney Tumors, Cysts and Treatment Options | Centennial AB**  
*Current approaches to caring for people with kidney manifestations including medical and surgical interventions.*

Moderator: **Lisa Moss**, Vice President, Donor Relations, TSC Alliance

Speakers: **Rachana Srivastava, MD**, Assistant Clinical Professor in the Division of Pediatric Nephrology at the David Geffen School of Medicine at UCLA; **Steven Raman, MD**, Director of Prostate MR Imaging and Interventions and UCLA Prostate MR Imaging Research Group

2:00-2:15 pm **BREAK | Centennial AB**

2:15-3:30 pm **Strategies for Managing Behaviors in TAND | Centennial AB**  
*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, Outreach & Support, TSC Alliance

Speakers: **Shafali Jeste, MD**, Professor and Mattel Executive Endowed Chair of Pediatrics, David Geffen School of Medicine, Executive Medical Director, Pediatrics, UCLA Health System; **Nicole McDonald, PhD**, HS Assistant Clinical Professor, Psychiatry and Biobehavioral Sciences, UCLA, Principal Investigator, McDonald Lab, Jane and Terry Semel Institute for Neuroscience and Human Behavior at UCLA Health; **Camila Ferrario, LMFT**, Psychotherapist, Behavioral Health Specialist, McDonald Lab, Jane and Terry Semel Institute for Neuroscience and Human Behavior at UCLA Health

3:30-3:45 pm **BREAK | Centennial AB**

3:45-4:15 pm **Ophthalmology | Centennial AB**  
*Vision plays an important role in understanding and managing TSC. This session will explore eye findings like retinal hamartomas, vision screening during vigabatrin treatment for infantile spasms, and how autism and developmental differences in TSC may impact eye contact and visual tracking.*

Moderator: **Elizabeth Skufca**, Community Programs Manager, TSC Alliance

Speaker: **Melinda Chang, MD**, Attending Physician, Assistant Professor of Clinical Ophthalmology, Keck School of Medicine of USC

4:15-5:30 pm

## Seizure Types and Treatments Through the Lifespan | Centennial AB

*How TSC impacts the brain, seizure types common in children and adults and an overview of rescue medication.*

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

Speakers: **Aria Fallah, MD, MS, MBA**, Director of Epilepsy Surgery at UCLA's Ronald Reagan Medical Center and Mattel Children's Hospital; **Donald Phillips, MD, MPH, FACNS, FAES**, Pediatric Epileptologist, CHOC, Medical Director, CHOC Comprehensive Epilepsy Center, Medical Director, CHOC Tuberous Sclerosis Complex (TSC) Center of Excellence, Medical Director, CHOC Neurophysiology Laboratories; **Raj Rajaraman, MD MS**, Epileptologist, Associate Professor, Director of the UCLA Tuberous Sclerosis Center of Excellence UCLA Mattel Children's Hospital David Geffen School of Medicine; **Vijay Vishwanath, MD, PhD**, clinic director of the CHLA TSC Center of Excellence and the CHLA Tics/Tourette Clinic, Attending Physician, Division of Neurology, Children's Hospital Los Angeles, Associate Professor of Neurology, USC Keck School of Medicine

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