



## Draft Agenda

Updated April 10, 2024

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|-----------------|--|
| 8:30 – 9:30 am  | <b>Check-in/Registration – Lobby</b>   |
| 9:30 – 10:45 am | <p><b>Welcome and Opening General Session: Research Updates and Upcoming Clinical Trials</b></p> <p>This opening session will provide an overview of the day and research updates on Anya’s Accelerator, Quality Improvement Initiatives and more.</p>   |
| 10:45 – 11 am   | <b>BREAK – Lobby</b>   |
| 11 am – 12 pm   | <p><b>Track 1: Pediatric- Seizure Types and Treatments: panel</b></p> <p>This session will provide information on how TSC impacts the brain, seizure types common in infants and children affected, and an overview of rescue medication.</p> <p><b>Track 2: Adult – Seizure Types and Treatments and Adult Seizure Action Plans: panel</b></p> <p>This session will provide information on how TSC impacts the brain, seizure types common in adults affected and using rescue medications.</p> |
| 12 – 1 pm       | <b>LUNCH</b>   |
| 1 – 2 pm        | <p><b>Track 1: Pediatric - Caregiver Mental Health and Well-Being</b></p> <p>This session will provide resources and information to empower caregivers to prioritize their mental health and well-being.</p>   |

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

This session will explore current approaches to caring for patients with kidney symptoms, including medical and surgical interventions.

2 – 2:15 pm

**BREAK - Lobby**

2:15 – 3:15 pm

**Track 1: Pediatric - Strategies for Managing Behaviors in TAND**

This session will provide an overview of TSC-associated neuropsychiatric disorders (TAND), and how to effectively navigate the system to access resources and support. It will include medical and non-medical interventions, when and how to use behavioral interventions, and practical tools and tips.

**Track 2: Adult - Skin Manifestations and Treatment Options**

This session will provide an overview of consensus guidelines, discuss treatment options (including surgical removal and FDA-approved medications) and highlight how clinical presentations vary across different skin tones.

3:15 – 3:30 pm.

**BREAK – Lobby**

3:30 – 4:30 pm

**General Session: Understanding the Genetics of TSC and family planning**

This session will provide 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.