



Chapel Hill Regional Conference Agenda
June 1, 2024 | Friday Conference Center at UNC Chapel Hill
Draft Agenda – Updated May 17, 2024

8:30 – 9:30 am	Check-In/Registration Atrium
9:30 – 10:45 am	<p>Welcome and Opening General Session: Research Updates and Upcoming Clinical Trials Redbud AB <i>This opening session will provide an overview of the day and research updates on Anya’s Accelerator, Quality Improvement Initiatives and more.</i></p> <p>Speakers:</p> <ul style="list-style-type: none"> • Shelly Meitzler, Director, Community Support & Outreach, TSC Alliance • Dean J. Aguiar, PhD, Vice President, Translational Research, TSC Alliance • Jamie Capal, MD, Associate Professor of Pediatrics and Neurology at the University of North Carolina at Chapel Hill and the Carolina Institute for Developmental Disabilities
10:45 – 11 am	BREAK Blueberry Hill
11 am – 12 pm	<p>Track 1: Pediatric– Seizure Types and Treatments Redbud AB <i>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.</i></p> <p>Moderator: Shelly Meitzler, Director, Community Support & Outreach, TSC Alliance</p> <p>Speakers:</p> <ul style="list-style-type: none"> • Jamie Capal, MD, Associate Professor of Pediatrics and Neurology at the University of North Carolina at Chapel Hill and the Carolina Institute for Developmental Disabilities • Mary T. Silvia, MD, Director, Wake Forest Baptist Medical Center Tuberous Sclerosis Clinic • Muhammad Zafar, MD, Co–Director, Tuberous Sclerosis Complex Center of Excellence, Duke Medical Center <p>Track 2: Adult – Seizure Types and Treatments and Adult Seizure Action Plans Dogwood AB <i>This session will provide information on 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 Speaker: Jane Boggs, MD, Co–Director, Wake Forest Baptist Medical Center Tuberous Sclerosis Clinic</p>
12 – 1 pm	LUNCH Trillium AB
1 – 2 pm	<p>Track 1: Pediatric – The Importance of Personalized Medicine in the Management of TSC in Community Living Settings Redbud AB <i>This session will provide resources and information to coordinate personalized medicine management of TSC in medical homes and other residential community settings.</i></p> <p>Moderator: Shelly Meitzler, Director, Community Support & Outreach, TSC Alliance</p>

Speakers:

- Klaus Georg Erich Werner, MD, PhD, Director, Tuberous Sclerosis Complex Center of Excellence, Duke Medical Center
- A. Bryn Salter, MD, Co-Director, Duke Medical Center

Track 2: Adult – Kidney Tumors, Cysts and Treatment Options | Dogwood AB

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

Moderator: Elizabeth Skufca, Community Programs Manager, TSC Alliance

Speaker: David Ortiz, MD, Duke University Hospital

2 – 2:15 pm

BREAK | Blueberry Hill

2:15 – 3:15 pm

Track 1: Pediatric – Strategies for Managing Behaviors in TAND | Redbud AB

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.

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

Speakers:

- Jamie Capal, MD, Associate Professor of Pediatrics and Neurology at the University of North Carolina at Chapel Hill and the Carolina Institute for Developmental Disabilities
- A. Bryn Salter, MD, Co-Director, Duke Medical Center

Track 2: Adult – Skin Manifestations and Treatment Options | Dogwood AB

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.

Moderator: Elizabeth Skufca, Community Programs Manager, TSC Alliance

Speaker: Elizabeth Nieman, MD, Pediatric Dermatology, University of North Carolina at Chapel Hill

3:15 – 3:30 pm

BREAK | Blueberry Hill

3:30 – 4:30 pm

General Session: Understanding the Genetics of TSC and family planning | Redbud AB

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.

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
- William Goodnight, MD, MSc, MFM, Physician, University of North Carolina