

Iowa City TSC Regional Conference Agenda

Tentative as of July 22, 2025 Iowa Memorial Union 125 N Madison St Iowa City, IA 52242

September 6, 2025

8:00-8:30 am Check-In/Registration

8:30-9:30 am Welcome and Opening General Session: Research Updates and Upcoming Clinical Trials |

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.

9:30-9:45 am **BREAK** |

9:45-11:00 am Seizure Types and Treatments Through the Lifespan

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

Speakers: Michael Ciliberto, MD; Brian Dlouhy, MD; Stephanie Randle, MD, MS

11:00-11:45 am **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.

Speaker: Alison Treichel, MD

11:45 am-12:45 pm LUNCH |

12:45-2:15 pm Genetics, Reproductive and Perinatal Health |

An overview of the genetics of TSC and the goals of the Reproductive and Perinatal Health Initiative by members of the Task Force. This panel discussion will include how genetics may play a role in family planning, pregnancy and care and treatment for mom and baby during pregnancy and after delivery.

Moderator: Heather Radtke, MS, CGC

Speakers: Lara Friel, MD; Lyndsay Harshman, MD, MS; Stephanie Randle, MD,

MS; Sarah Weatherspoon, MD

2:15-2:30 pm **BREAK** |

2:30-3:30 pm Kidney Tumors, Cysts and Treatment Options |

Current approaches to caring for people with kidney symptoms including medical

and surgical interventions.

Speakers: Lyndsay Harshman, MD, MS; Rachel Kinn, PharmD, BCPPS

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

3:45-5:00 pm Social resources for medically complex patients - bridging the pediatric to

adult transition of care

An overview of the resources and supports to utilize for the transition from

pediatric to adult care.

Speaker:

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