



draft agenda as of 7.9.24

8:30 – 9:00 am

Check-In/Registration

9 – 10:30 am

Medical Transition Guidelines and Toolkit

Why it is important to start planning early when transitioning medical care from the pediatric to adult health system and how to use a transition toolkit.

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

Speakers: John J. Bissler, MD, Director; James W. Wheless, MD and Sarah Weatherspoon, MD, Co-Directors; Tanjala T. Gipson, MD, TAND Unit Director, Tuberous Sclerosis Center of Excellence at Le Bonheur Children's Hospital

10:30 – 11:00 am

Break

11 am – 12:30 pm

Navigating the Education System

How to access resources and support services for independent adults with TSC pursuing postsecondary education and information about vocational and postsecondary opportunities for semi-independent and dependent adults with TSC.

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

Speaker: Elizabeth Skufca, Community Programs Manger, TSC Alliance

12:30 – 1:30 pm

Lunch

1:30 – 3 pm

Track 1: Transition into Adulthood: Employment and Higher Education

Examining issues independent young adults face in the workplace and higher education and how to access support resources.

Moderator: Elizabeth Skufca, Community Programs Manager, TSC Alliance

Track 2: TAND: Mental Health issues in Living with TSC for Semi Independent and Dependent Adults

Discussing mental health issues of TSC-associated neuropsychiatric disorders (TAND) including aggression, self-injurious behaviors and how to access support resources.

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

Speaker: Tanjala T. Gipson, MD, TAND Unit Director, Tuberous Sclerosis Center of Excellence at Le Bonheur Children's Hospital

3 – 3:30 pm

Break

3:30 - 5 pm

Track 1: TAND: Mental Health issues in Living with TSC as an Independent Adult

Discussing mental health issues of TSC-associated neuropsychiatric disorders (TAND) including anxiety, executive function, exhaustion faced by adults with TSC and how to seek support.

Speaker: Tanjala T. Gipson, MD, TAND Unit Director, Tuberous Sclerosis Center of Excellence at Le Bonheur Children's Hospital

Track 2: Guardianship and Financial Planning for Semi Independent and Dependent Adults

An overview of support resources for dependent and semi-independent care that include SSI, waivers, Medicaid, financial planning and guardianship.

5 - 5:30 pm

Question and Answer Session