"Support for the medical transition of youth living with neurological conditions is a small but critical acknowledgement that youth should not simply survive into adulthood: they should thrive as adults."[1]

– Child Neurology Foundation

Transitioning TSC patients with neurologic manifestations from pediatric to adult care

As a chronic disease with an unpredictable course, tuberous sclerosis complex (TSC) requires lifelong, ongoing surveillance[2]

- **TSC-associated neuropsychiatric disorders (TAND)** and epilepsy can be present throughout life[2,3]
- **Renal manifestations** require significantly more monitoring and intervention as patients get older[2]
- **Lymphangioleiomyomatosis** develops in adults and can cause serious pulmonary issues[2]

Proper transitioning from pediatric to adult care is critical for TSC patients[4]

Transition planning can help to[2,4]:

- Prevent gaps in care
- Avert preventable health crises
- Avoid duplicative tests and services
- Ensure appropriate monitoring and symptom management to prevent more costly medical complications

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Child Neurology FOUNDATION
Creating a Community of Support

Tuberous Sclerosis Alliance

The Child Neurology Foundation Guidelines on Transitioning Youth to Adult Health Care[4]

The following guidelines for child neurology teams are based on a consensus statement issued by the Neurology Transition Consensus panel, an interdisciplinary team of medical professionals, neurology patients, and family members of patients.

BY AGE 13

- ☐ **Discuss the expected transition to adult health care with youth and caregiver(s)**

BEGINNING ~AGE 13

- ☐ **Assess youth's self-management skills annually**
  - > Document assessments
  - > Communicate to other health care providers
- ☐ **Work with youth and caregiver(s) in phased transition planning, education, and transfer readiness annually**
- ☐ **Include youths with intellectual disabilities in the process, with discussions targeted to caregiver(s)**

BEGINNING AT AGE 14

- ☐ **Begin discussion regarding youth's legal competency (eg, need for legal guardianship, powers of attorney)**
- ☐ **Begin developing transition plan; child neurology team is responsible for neurology content**
- ☐ **Ensure plan is based on collaboration with youth, caregiver(s), health care providers, school personnel, legal services (as needed)**

1 TO 2 YEARS BEFORE TRANSITION

- ☐ **Work with youth and caregiver(s) to identify appropriate adult care provider(s) for the neurologic condition(s)**

AT TIME OF TRANSITION

- ☐ **Send adult provider(s) a transfer packet, including the transition plan and medical summary**
- ☐ **Confirm adult provider(s) has agreed to accept patient**
- ☐ **Document the transfer**

Visit www.neurology.org for a free copy of the complete guidelines.

AT YEARLY VISIT BEFORE THE TRANSFER OF CARE, PLAN TO ADDRESS:

- > Current medical condition
- > Current medications/ potential side effects
- > Signs and symptoms of concern
- > Genetic counseling
- > Issues of puberty and sexuality
- > Driving, alcohol and substance use, other risks
- > Emotional/psychological concerns and wellness

THESE GUIDELINES ARE ENDORSED BY AND/OR ALIGNED WITH:

American Academy of Neurology | **American Epilepsy Society** | **Child Neurology Society** | **American Academy of Pediatrics**

References: 1. Transitioning youth to the adult healthcare system. Child Neurology Foundation website. http://www.childneurologyfoundation.org/advocates/transitioning-youth-to-the-adult-healthcare-system/. Accessed November 16, 2016. **2.** Krueger DA, Northrup H; International Tuberous Sclerosis Complex Consensus Group. Tuberous sclerosis complex surveillance and management: recommendations of the 2012 International Tuberous Sclerosis Complex Consensus Conference. *Pediatr Neurol.* 2013;49(4):255-265. **3.** French JA, Lawson JA, Yapici Z, et al. Adjunctive everolimus therapy for treatment-resistant focal-onset seizures associated with tuberous sclerosis (EXIST-3): a phase 3 randomised, double-blind, placebo-controlled study. *Lancet.* 2016;388:2153–2163. **4.** Brown LW, Camfield P, Caper M, et al. The neurologist's role in supporting transition to adult health care: a consensus statement. *Neurology.* 2016;87(8):834-840.

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