"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.”

– 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

> **TSC-associated neuropsychiatric disorders (TAND)** and epilepsy can be present throughout life

> **Renal manifestations** require significantly more monitoring and intervention as patients get older

> **Lymphangioleiomyomatosis** develops in adults and can cause serious pulmonary issues

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

**Transition planning can help to:**

> 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

Brought to you by Novartis Pharmaceuticals Corporation, in partnership with
The Child Neurology Foundation Guidelines on Transitioning Youth to Adult Health Care

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

**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