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TSC Alliance and Tuberous Sclerosis Complex Clinics Standard of Care Metrics*

Purpose of Standards of Care for TSC Clinics and Centers of Excellence

Many manifestations of TSC can be life-changing and even life-threatening and appropriate surveillance and management is necessary to limit morbidity and mortality in this disease. Appropriate management is also crucial for optimal quality of life of affected individuals and requires coordination of care among medical specialties and from childhood to adulthood on a regular basis. In 2013, recommendations using the best available scientific evidence for the optimal clinical management of patients with TSC were published (Krueger, Northrup, *et al. Pediatric Neurology* 49:255-265). These are the basis for evaluating the quality of clinical care each TSC Clinic and TSC Center of Excellence clinical care is expected to provide.

Metrics for Assessing Standards of TSC Care: Medical

1. Brain: Subependymal Giant Cell Astrocytoma (SEGA), Epilepsy, and TSC-associated Neuropsychiatric Disorders (TAND).

For the most recently completed calendar year:

- a. Among patients under the age of 21 years, the percentage at least one MRI of the brain obtained within the past 3 years.
- b. Among patients presenting with infantile spasms, the percentage for which therapy with vigabatrin was initiated as first-line treatment.

Hope no matter how complex



- c. Among patients under the age of 1 year with new-onset seizures, the percentage for which treatment was initiated within 7 days after first contact with the TSC Clinic or Center.
- d. Among patients with TAND-related concerns, the percentage who are referred for additional evaluation and/or treatment.

2. **Kidney: Angiomyolipomas and Renal Cysts.**

For the most recent calendar year:

- a. Among all TSC patients, the percentage having at least one MRI of the kidneys obtained within the past 3 years.
- b. Among all TSC patients, the percentage having blood pressure and glomerular filtration rate assessment in the past year.
- c. Among all TSC patients with hypertension or reduced renal function, the percentage referred to nephrology in the past year.

3. **Lung: Lymphangiomyomatosis (LAM) and Multifocal Microdonular Pneumocyte Hyperplasia (MMPH).**

For the most recent calendar year:

- a. Among adult females (>21 years), the percentage having at least one chest CT in the past 5 years.
- b. Among adult females (>21 years), the percentage counseled against smoking and exogenous estrogen use.

4. **Heart: Rhabdomyomas and Arrhythmias.**

For the most recent calendar year:

- a. Among patients under the age of 3 years, the percentage having at least one echocardiogram.
- b. Among patients under the age of 3 years, the percentage having at least one electrocardiogram.

- c. Among patients over the age of 3 years, the percentage having at least one electrocardiogram obtained within the past 5 years.

5. **Skin: Hypomelanotic Macules, Angiofibromas, Cephalic Plaques, Ungual Fibromas, and Shagreen Patches.**

For the most recent calendar year:

- a. Among all TSC patients, the percentage with documented skin examination of TSC-related findings in the past year.

6. **Eye: Retinal Hamartomas and Retinal Achromic Patches.**

For the most recent calendar year:

- a. Among patients with TSC ocular involvement, the percentage referred to ophthalmology.
- b. Among patients treated with vigabatrin, the percentage referred to ophthalmology in the past year.

7. **Genetics: Diagnostic Confirmation and Family Counseling.**

For the most recent calendar year:

- a. Among all TSC patients, the percentage offered genetic testing (individual or other family members) if not done previously.
- b. Among patients of reproductive age, the percentage provided genetic counseling.

Metrics for Assessing Standards of TSC Care: Patient Experience

For the most recently completed calendar year, among all TSC patients, the percentage completing the *TSC Clinic Patient and Family Experience of Care Survey*.

***NOTE:** *In 2020, TSC Standards of Medical Care and TSC Clinic Patient and Family Experience of Care Survey were newly updated and integrated into the TSC Clinical Designation Review and Approval Process. The TSC Alliance TSC Clinic Committee, a sub-committee of the Science and Medical Committee of the TSC Alliance Board of Directors, has yet to determine individual item metrics for each standard. These will be incorporated into future versions of the current document when available and revised/updated as appropriate. This includes*

addition of survey item metrics that capture clinic communication and coordination of care, clinician expertise in TSC, clinician knowledge of the individual patient's condition, and overall satisfaction with the in-clinic experience and quality of care provided.

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