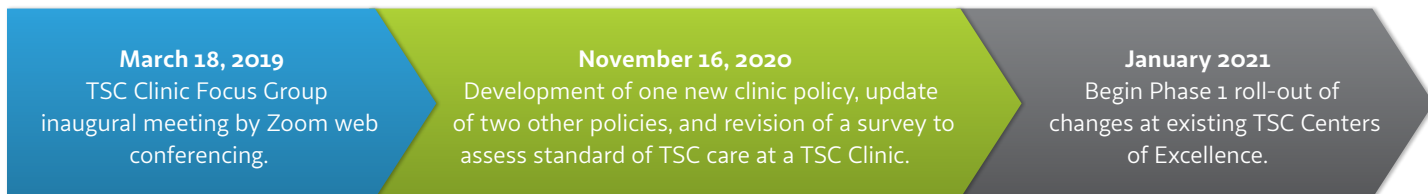


TSC Clinic Focus Group Results:

Changes to TSC Clinic Standards and Recognition Process



In March 2019, the Tuberous Sclerosis Alliance formed a TSC Clinic Focus Group comprised of staff, TSC community members and healthcare providers to critically evaluate the existing TSC clinic criteria for recognition as a TSC Clinic or TSC Center of Excellence. The objectives were to create a transparent and effective review process that encourages and recognizes excellence and expertise in caring for individuals with TSC. This group met regularly for nearly two years.

After completing a SWOT (strength, weakness, obstacles, threats) analysis, the group used it to guide its work to:

- **Create a Standard of Care Metrics for TSC Centers of Excellence and TSC Clinics.** The recommendations of the 2012 International TSC Consensus

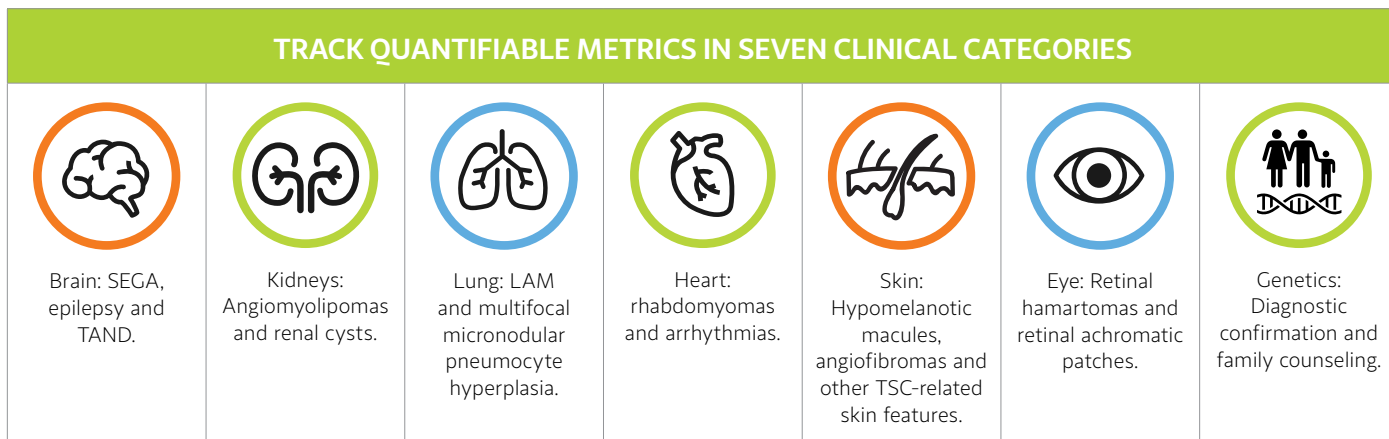
Conference published in 2013 (Krueger, Northrup, et al. *Pediatric Neurology* 49:255-265) serve as the basis for evaluating the quality of care a TSC Clinic and TSC Center of Excellence are expected to provide. The TS Alliance will collect baseline metrics at TSC Centers of Excellence in seven clinical categories (see Figure 1), which will be incorporated into the TSC Clinic Designation Review and Approval Process.

- **Update the TSC Patient and Family Experience of Care Survey**, which will be integrated into the TS Alliance recognition and designation renewal process.
- **Update the TSC Clinic Structure and Expertise Requirements for TSC Centers of Excellence and TSC Clinics.** The Focus Group recommended more stringent guidelines to promote

minimum standard of care through a TSC Clinic but recognize added services and expertise at a TSC Center of Excellence. Differences between a TSC Clinic and a TSC Center of Excellence are summarized in the table on page 15. More details about the TSC Clinic Structure and Expertise will be posted on the TS Alliance website. For additional information, you may also contact Jo Anne Nakagawa at jnakagawa@tsalliance.org or (240) 638-4654.

- **Update the TS Alliance and TSC Clinics Scope of Relationship Policy.** This policy describes each entity's role.
- **Update the TSC Clinic Designation Review and Approval Process for new applications and renewals.** The recognition and designation will focus on the clinic rather than the Director.

Figure 1



Proposed Timetable to Implement Changes

Beginning January 2021, changes to the TSC Clinic standards and recognition process will be implemented gradually at U.S.-based TSC Centers of Excellence and TSC Clinics. New applications will not be accepted until July to allow for transition to the new process. In 2022, the policies will be adapted for implementation at international TSC Clinics affiliated with our Global Alliance partners.

TSC Clinic Focus Group Members

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- **Laura Lubbers, PhD** (TSC Family Member; Chief Scientific Officer, CURE Epilepsy)
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- **David Parkes** (TSC Parent)
- **E. Steve Roach, MD** (TS Alliance Professional Advisory Board Member)
- **Kari Luther Rosbeck** (TS Alliance President & CEO)
- **Bonnie Gould Rothberg, MD PhD** (TSC Parent)
- **Julie Scroggins** (TSC Parent; TS Alliance Community Programs Manager, West)
- **Sean Shillinger** (TSC Parent)
- **Jackie Tallman** (TSC Parent)

Table: Differences Between a TSC Clinic and a TSC Center of Excellence.

CATEGORY	TSC CLINIC	TSC CENTER OF EXCELLENCE (COE)
Age range	Pediatric, Adult, or All Ages	Pediatric, Adult or All Ages. However, a COE that does not provide care for all ages is required to have well-established procedures for coordinating and transitioning care with specialists for anyone with TSC outside of the age range or medical services their TSC Center is able to provide or manage.
Services Provided *Essential services: Neurology, Nephrology, Pulmonology (Adult), Genetics, Psychiatry/ Psychology or Developmental Pediatrics, Cardiology, Ophthalmology and Dermatology.	All essential services for diagnosis and management of major aspects of TSC are provided.*	All essential services for diagnosis and management of major aspects of TSC are provided.*
	Director must have a minimum of one-year TSC experience.	Director must have a minimum of 5 years TSC experience.
		Additional multispecialty services are available with expertise in TSC for individuals with advanced disease, medical complications, or in need of advanced treatment options or access to new and emerging interventions.
	Clinic has a dedicated coordinator as the point of contact for patients, specialists, and TS Alliance.	Clinic has a dedicated coordinator as the point of contact for patients, specialists and TS Alliance.
	Refer individuals with more complex, rare or advanced manifestations resulting in significant disability, medical complications, or in need of advanced specialty services to an affiliated COE.	Serves as a resource and referral destination to TSC Clinics regionally and nationally for individuals with rare manifestations, complications, or in need of advanced specialty care or treatment options.
	Schedule a minimum of one clinic per month specifically for TSC care.	Schedule multiple clinics per month specifically for TSC care.