

Tuberous Sclerosis Clinic

at Kennedy Krieger Institute

Who We Are

The Tuberous Sclerosis Clinic at Kennedy Krieger Institute is nationally recognized by the Tuberous Sclerosis Alliance as a specialized clinic dedicated to the comprehensive care of children, adolescents and young adults with tuberous sclerosis complex (TSC). At our clinic, patients and families work with an interdisciplinary team of clinicians who specialize in evaluating and caring for individuals with epilepsy and neurologic and neurodevelopmental differences. We're dedicated to caring for the whole individual and supporting families along their TSC journey.

Who We Serve

TSC is a rare genetic condition in which noncancerous tumors form in multiple systems throughout the body, including in the brain, heart, lungs, kidneys and other organs. It occurs in approximately one in 10,000 births and affects 1 to 2 million individuals worldwide. Individuals with TSC experience variations in organ involvement, cognitive delays, seizures, and mood and behavior difficulties throughout their lives. We provide patients with expert care that addresses these concerns.

Our Approach and Team

Our treatment model emphasizes individualized, comprehensive, coordinated care through an interdisciplinary model.

During initial evaluations, patients receive detailed medical, developmental and educational screenings by our pediatric neurologists and neuropsychologist, as well as a genetic evaluation with a genetic counselor. Subsequent appointments include evaluations with our pediatric neurologists, and with our neuropsychologist, pediatric epileptologist and pediatric nephrologist, when needed.

Additional testing and subspecialty evaluations may be required to determine the extent to which an individual is affected by TSC. These tests may include:

- MRI of the brain and/or abdomen
- Dilated eye exam and ophthalmologic screening
- Ultraviolet light examination of the skin
- EEG
- Laboratory tests



Our interdisciplinary team incorporates experts from Kennedy Krieger and Johns Hopkins Medicine, with specialists from multiple disciplines, including:

- Behavioral psychology
- Pediatric cardiology
- Pediatric ophthalmology
- Pediatric nephrology
- Pediatric rehabilitation medicine (including physical and occupational therapists)
- Neuropsychiatry
- Neurosurgery (for epilepsy surgery)
- Sleep medicine
- Speech-language pathologists
- Assistive language technologists

Our team works closely with families and specialists to monitor progress over time and adjust care as patients grow and their needs evolve. This approach allows us to identify concerns early, coordinate efficiently, and create a tailored plan that supports each patient and their family in everyday life.

Research and Collaborations

Our clinical care is driven by ongoing research to ensure that patients and families receive the most innovative therapies. We're committed to improving their lives by designing and participating in clinical and preclinical research.

Our current projects include:

- Understanding gender differences in TSC-associated neuropsychiatric disorders (TAND)
- Examining the neurocognitive and neuropsychiatric profile of individuals with TSC across the lifespan to deepen our understanding of how TSC affects behavior, cognition and daily functioning
- Investigating pharmacologic and non-pharmacologic therapies for refractory epilepsy in TSC

An additional strength of our clinic is our commitment to seamless pediatric-to-adult transition planning for patients between 18 and 21 years old. Our TSC-specific transition questionnaires and tool kits help guide families through the transition process. We also collaborate with the Tuberous Sclerosis Complex Center of Maryland at the University of Maryland to optimize continuity of care. This partnership supports smooth transitions, reduces gaps in care and helps ensure young adults receive expert TSC management into adulthood.

Our clinic is proud to offer compassionate, coordinated, research-informed care that supports the whole individual and their family.

CONTACT US

Tuberous Sclerosis Clinic at Kennedy Krieger Institute

Please email TSC@KennedyKrieger.org or call **443-923-2746** for more information. To register yourself or your child as a patient at Kennedy Krieger Institute, please call **443-923-9400**, or call toll-free at **888-554-2080**. TTY users, please contact us at **443-923-2645**, or dial **711** to make a Maryland Relay call.

[KennedyKrieger.org/TuberousSclerosisClinic](https://www.KennedyKrieger.org/TuberousSclerosisClinic)

Physicians and Healthcare Professionals

To make a referral, email us at FindASpecialist@KennedyKrieger.org or call our Physician Referral Line at **443-923-9403**.

Clinic Location

801 North Broadway
Baltimore, MD 21205

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