

Tuberous Sclerosis Clinic at Kennedy Krieger Institute

Who We Are

The Tuberous Sclerosis Clinic at Kennedy Krieger Institute is recognized by the TSC Alliance as a clinic dedicated specifically to the care of individuals affected by tuberous sclerosis complex (TSC) and their families. Occurring in an estimated one in 6,000 live births worldwide, TSC is a genetic disorder that causes noncancerous tumors to form in many different organs, including the brain, eyes, heart, kidneys, skin and lungs. Signs and symptoms of the condition vary from person to person. As a result, TSC may be unrecognized or misdiagnosed for years.

Who We Serve

We provide expert care for children, adolescents and adults who experience conditions associated with TSC. Although we place special emphasis on the identification and treatment of epilepsy, autism spectrum disorder, intellectual disabilities, learning disabilities, anxiety, ADHD and behavioral challenges (including self-injury and aggression) in individuals with TSC, our clinic works with anyone with the disorder, as well as their families.

Our Team

Our clinic includes an interdisciplinary team of healthcare professionals trained and experienced in treating and managing individuals with TSC. This interdisciplinary approach is specifically designed to care for individuals with TSC with multiple medical needs and complexities.

We perform a comprehensive evaluation of each patient to ensure a thorough examination of their unique needs. Our interdisciplinary team of clinicians from across the Institute and Johns Hopkins Medicine includes specialists from the following disciplines:

- Assistive technology
- Behavioral psychology
- Child neurology
- Child psychiatry
- Educational services
- Epilepsy (surgery)
- Genetic counseling
- Neurogenetics
- Neuroimaging
- Neurology
- Neurophysiology
- Neuropsychology
- Neurosurgery
- Occupational therapy
- Pediatric cardiology
- Pediatric dermatology
- Pediatric epileptology
- Pediatric nephrology
- Pediatric neuro-oncology
- Pediatric ophthalmology
- Physical therapy
- Psychiatry
- Sleep medicine
- Social work
- Speech-language pathology



Our Approach

TSC varies dramatically in severity, so our treatment model emphasizes unique care regimens tailored to each patient.

When patients first arrive in our clinic, they receive an initial evaluation by our clinic director, Dr. Ryan E. Gill, a neurodevelopmental pediatrician and epileptologist. In some cases, additional testing may be required to determine the extent of the condition.

These tests may include:

- MRI of the brain and/or abdomen
- Dilated eye exam
- Genetic testing
- Ultrasound of the kidneys
- Ultraviolet light examination of the skin

Depending on individual need, further care may include medical or rehabilitation services offered at Kennedy Krieger, or referral for surgical intervention. Follow-up care typically occurs every three to six months.

Although there is no cure for TSC, quality care from experts who understand the condition is key to helping individuals successfully manage symptoms, overcome obstacles and succeed in family, school and community life.

Research and Collaborations

The Institute's clinical care is driven by its ongoing research, which ensures that patients receive the most innovative therapies available. Our clinic's team is committed to improving the lives of patients and families with TSC through designing and participating in existing research studies, both clinical and preclinical.

Current research efforts are aimed at using magnetic resonance (MR) spectroscopy technology to help understand the biochemical factors affecting seizure activity and cognition in TSC. The clinic is also a site for clinical trials investigating therapies for refractory epilepsy (also known as drug-resistant epilepsy), in TSC.

Contact Information

Tuberous Sclerosis Clinic at Kennedy Krieger Institute

For more information, please call **443-923-2746** or email **TSC@KennedyKrieger.org**. 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

Physicians and Healthcare Professionals

To make a referral, call our Physician Referral Line at **443-923-9403**.

Clinic Location

801 North Broadway
Baltimore, MD 21205

Mailing Address

707 North Broadway
Baltimore, MD 21205

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