

Rett Syndrome Clinic at Kennedy Krieger Institute

Who We Are

Rett syndrome (RTT) is a neurological disorder that affects girls almost exclusively. It is characterized by normal early growth and development followed by a slowing of development, usually around 1½ to 3 years of age, with loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, loss of language skills, seizures, and intellectual disability. Rett syndrome is caused by mutations in the *Mecp2* gene.

Kennedy Krieger Institute, through its Neurology and Neurogenetics Clinic, is one of the few healthcare providers in the mid-Atlantic that diagnoses and treats this syndrome. We provide comprehensive medical evaluations, clinical care and genetic testing. In addition to our expertise in this very rare disorder, our interdisciplinary resources mean that our patients' needs can be met at one location. It is our goal to help our patients and their families gain a better understanding of the condition and access appropriate medical care and therapeutic interventions to improve their overall health and quality of life.

Who We Serve

The Rett Syndrome Clinic at Kennedy Krieger provides expert diagnostic services and treatment for children, adolescents and adults with Rett syndrome and associated disorders.

Diagnosing Rett Syndrome

Clinical genetic testing for Rett syndrome is done using standard genome sequencing and deletion/duplication testing. If a genetic diagnosis has not yet been made, a genetic counselor guides patients and their families through the diagnostic process. Based on the results of such testing and the initial evaluation, our team develops an individualized care plan, modifying it as the patient's needs change over time.

Our Team

Kennedy Krieger is home to a unique interdisciplinary collaboration of Rett syndrome experts. Our clinicians, research scientists and rehabilitation professionals work together to provide optimal interdisciplinary care for patients. Because Rett syndrome can affect many different systems in the body, treating a patient with the disorder often requires the collaboration of a wide range of medical specialists. Key specialists who see our patients include those in the following fields:

- Assistive communication
- Bone specialists
- Gastroenterology
- Genetic counseling
- Neurology
- Nutrition
- Occupational therapy
- Orthopedics
- Physical therapy
- Speech and language therapy

Treatment

Each patient's treatment plan includes individualized interventions designed to help the patient cope with the loss of abilities, improve or preserve function, manage seizures, and communicate via advanced technologies like eye gaze communication devices. These interventions address the full spectrum of clinical concerns.

Additionally, we can also facilitate access to Kennedy Krieger's comprehensive team of specialists to assist with specific educational, behavioral and other therapy needs.

Contact Information

Rett Syndrome Clinic at Kennedy Krieger Institute

For more information or to schedule an appointment, 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

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

Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Kennedy Krieger Institute provides care that preserves cultural, psychosocial, spiritual and personal values, beliefs and preferences. Care is free from discrimination based on age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression, including transgender. We encourage patients and families to become active partners in their care by asking questions, seeking resources and advocating for the services and support they need. © 2018 Kennedy Krieger Institute 10/18

