

# Kennedy Krieger Pediatric Neurofibromatosis Program

at the Johns Hopkins Comprehensive Neurofibromatosis Center

## Who We Are

Neurofibromatosis (NF) is a group of genetic conditions that can affect multiple organ systems, including the brain, skin, bones and other parts of the body. Children with NF may also experience developmental, learning, behavioral and emotional difficulties. Because symptoms can vary widely, early identification and coordinated, ongoing care are essential.

The Kennedy Krieger Pediatric Neurofibromatosis Program, in collaboration with the Johns Hopkins Comprehensive Neurofibromatosis Center, provides comprehensive, interdisciplinary care that integrates specialized medical expertise with neurodevelopmental evaluation and treatment. This unique partnership allows us to deliver coordinated, developmentally informed care designed to improve outcomes and quality of life for children with neurofibromatosis.

## Who We Serve

We provide expert care for infants, children and adolescents, from birth through age 16, including:

- Children with suspected or confirmed NF1 or schwannomatosis, including NF2-related schwannomatosis
- Children with features suggesting they might have NF (e.g., café-au-lait spots, developmental differences or family history)
- Children undergoing evaluation for possible NF
- Children with genetic findings consistent with NF
- Children with segmental or mosaic NF and NF1-like syndromes (e.g., Legius syndrome)

We also provide education, guidance and support for families navigating diagnosis, monitoring and long-term care.

## Our Team

Children with NF often benefit from coordinated developmental and rehabilitation services available through Kennedy Krieger, including:

### Developmental and Behavioral Services

- Autism diagnostic evaluations
- Clinical psychology services
- Behavioral therapy and parent support
- Neuropsychological evaluations
- Education advocacy and school support

### Rehabilitation and Therapy Services

- Speech-language therapy
- Occupational therapy
- Physical therapy
- Neurorehabilitation
- Assistive technology services

### Feeding and Nutrition Services

- Feeding Disorders Program
- Nutrition services

### Medical and Support Services

- Genetics and genetic counseling
- Neurology
- Neurodevelopmental care
- Sleep medicine

Because NF can affect multiple organ systems, our program collaborates closely with pediatric subspecialists across Johns Hopkins Medicine, including those working in:

- Cardiology and vascular surgery
- Dermatology
- Endocrinology
- ENT and audiology
- Genetics
- Hematology and oncology



- Neurology
- Neuro-oncology
- Neurosurgery
- Ophthalmology
- Oral and craniofacial surgery
- Orthopedics
- Pain management
- Plastic and reconstructive surgery
- Radiology and neuroradiology

The Kennedy Krieger Pediatric Neurofibromatosis Program is led by a dedicated pediatric team embedded within the broader Johns Hopkins Comprehensive Neurofibromatosis Center. This integrated model allows families to benefit from coordinated, interdisciplinary expertise across both Kennedy Krieger and Johns Hopkins Medicine.

## Our Approach

Neurofibromatosis presents differently in every child. Our care model emphasizes individualized, ongoing care tailored to each child’s medical and developmental needs.

Our comprehensive evaluation may include:

- Medical and neurological assessment
- Developmental and behavioral evaluation
- Genetic counseling and testing, when appropriate
- Neuropsychological or cognitive assessment
- Review of previous imaging and specialty evaluations

Following the evaluation, we develop a personalized care plan that may include:

- Ongoing medical monitoring
- Developmental and behavioral supports
- Therapy services
- School and education guidance
- Referral to subspecialty providers, as needed

We care for our patients over time, with appointment frequency based on a patient’s individual needs and developmental stage. When a patient enters adolescence, we work closely with their family to support the patient’s transition to adult NF care through the Johns Hopkins Comprehensive NF Center.

## Why Choose Our Program

- Comprehensive care from birth through adolescence
- Ongoing care with planned transition to adulthood
- Interdisciplinary, developmentally informed approach
- Access to specialized therapies and services
- Close collaboration with Johns Hopkins specialty experts
- Integration of clinical care and research

## CONTACT US

**Kennedy Krieger Pediatric Neurofibromatosis Program at the Johns Hopkins Comprehensive Neurofibromatosis Center**

For more information or to schedule an appointment, please email [NeurologyCoordinatorsReferrals@KennedyKrieger.org](mailto:NeurologyCoordinatorsReferrals@KennedyKrieger.org) or call **410-502-6732**, 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, email us at [FindASpecialist@KennedyKrieger.org](mailto:FindASpecialist@KennedyKrieger.org) or call our Physician Referral Line at **443-923-9403**.

**Program Location**  
801 North Broadway  
Baltimore, MD 21205

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