

# Clinical Connection

News, Updates, and Support for Healthcare Professionals



Kennedy Krieger Institute  
UNLOCKING POTENTIAL

REHABILITATION • DEVELOPMENTAL MEDICINE • BEHAVIORAL THERAPIES



Dear Colleague,

For over 75 years, Kennedy Krieger Institute has been a national leader in providing patient care for children and young adults with disorders and injuries of the brain, spinal cord, and musculoskeletal system.

Our medical staff of more than 200 physicians, representing more than 50 specialties, and a staff of more than 2,400 dedicated employees provide your patients unique access to the latest in research and treatment models in the areas of neurorehabilitation, behavioral disorders, and other developmental disorders.

To ensure that your patients receive the best care possible, we take an interdisciplinary team approach that starts with you, the referring physician. Our staff works closely with you and your patients and families to develop comprehensive and individualized treatment plans. Depending on their needs, we can offer your patients care in a variety of settings, including a 70-bed inpatient unit, outpatient programs that see more than 20,000 patients each year, day treatment services, and home- and community-based programs.

In addition to the news, updates, and inspiring stories you'll find inside *Potential* magazine, we've provided an overview of the Institute's programs and services, as well as clinical and research updates. If you have any questions or would like to learn more about any of our patient care programs, please call our Physician Referral Line at **443-923-9403** or email us at **FindASpecialist@KennedyKrieger.org**.

Sincerely,  
Gary W. Goldstein, MD

## OUR CULTURE OF CARE

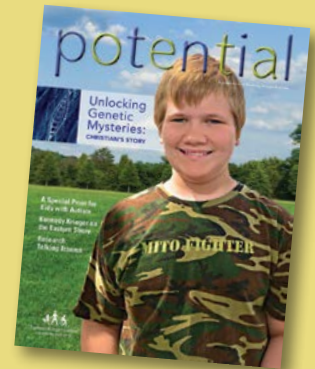
Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Care is provided in a manner that preserves cultural, psychosocial, spiritual and personal values, beliefs, and preferences. We encourage patients and families to become active partners in their care by asking questions, requesting resources, and advocating for the services and support they need.

## PROGRAM NEWS & UPDATES:

- Help for Patients with Feeding Disorders
- Sleep Studies for Children with Challenging Behaviors
- NICU Follow-up for Infants at Risk
- Research Study Recruiting

## INSIDE POTENTIAL MAGAZINE:

- **Exome sequencing:** Unlocking genetic mysteries
- **Short-term intensive therapy** boosts independence
- Research: The **epigenetics of childhood trauma**
- Kennedy Krieger **on the Eastern Shore**



Visit **PotentialMag.KennedyKrieger.org** to access articles and search publication archives.

## REFERRING YOUR PATIENTS

To support the needs of physicians and healthcare professionals, our care management team is available to provide information on appropriate clinical programs, handle referrals, obtain consultations with Institute specialists, and schedule appointments for patients and families.

Call **443-923-9403** to reach our Physician Referral Line or visit **Referrals.KennedyKrieger.org** for information and resources for physicians and healthcare professionals.

For general information, call **1-888-554-2080** or visit **KennedyKrieger.org**.

## HELP FOR PATIENTS WITH FEEDING DISORDERS



The Pediatric Feeding Disorders Program at Kennedy Krieger Institute is one of the leading programs in the country offering evidence-based, inpatient, day, and outpatient treatment for children with feeding disorders. A team of interdisciplinary pediatric specialists works collaboratively to identify the factors affecting a child's eating behavior and create an individualized treatment plan with each child and family.

Our approach not only incorporates each child's complex medical and developmental needs, but also addresses behavioral and oral-motor feeding issues, in order to improve outcomes.

Feeding disorders affect a child's ability to properly function at home, at school, and in other social settings, and impact a child's physical, social, and psychological development. Common signs and symptoms of a feeding disorder include:

- Poor weight gain
- Limited oral intake
- Bottle or formula dependence
- Tantrums or extreme length of mealtimes
- Distress and anxiety with new foods
- Trouble chewing or swallowing different food textures
- Inability or refusal to feed oneself
- Extreme pickiness

We treat children both with and without developmental disabilities, including children with Down syndrome and autism spectrum disorders, as well as NICU graduates. If you have a patient with feeding difficulties, contact our Physician Referral Line at **443-923-9403** or email us at [FindASpecialist@KennedyKrieger.org](mailto:FindASpecialist@KennedyKrieger.org).

## NICU FOLLOW-UP FOR INFANTS AT RISK

The NICU Follow-up Clinic provides developmental evaluation and treatment of infants at high risk for developmental delays based on diagnosis or complications during prenatal or neonatal life.

Referrals are recommended for infants who were born prematurely or who have been seriously ill in the nursery. This includes infants who:

- Experience brain injury, such as neonatal brain hemorrhage
- Experience neurologic complications in the NICU
- Have genetic disorders identified in the nursery
- Have low birth weight

For up to three years following birth, ongoing comprehensive care for a range of complex issues is provided by an interdisciplinary team of healthcare professionals to help ensure the best possible outcomes for each child—all in one location for the convenience of families. These professionals include:

- Nurse practitioners trained in neonatology
- Neonatal developmental specialists
- Neurodevelopmental specialists
- Neuropsychologists
- Nurses with specialized training in neonatology
- Physical therapists

Additional support and services can also be provided as needed by specialists in feeding and nutrition, occupational therapists, speech therapists, audiologists, and orthopedists.

For more information or to make a referral to the NICU Follow-up Clinic, please call our Physician Referral Line at **443-923-9403** or email us at [FindASpecialist@KennedyKrieger.org](mailto:FindASpecialist@KennedyKrieger.org).



## SLEEP STUDIES FOR CHILDREN WITH CHALLENGING BEHAVIORS



Children with neurodevelopmental disorders (NDD) are at increased risk for sleep disorders, which can adversely affect a child's health, development, and behavior. Sleep disorders are treatable conditions, but may require polysomnography during an overnight sleep study for diagnosis. Children with NDD are often intolerant of sleep studies due to anxiety, behavioral problems, and sensory sensitivities to the equipment, such as a nasal cannula. The Pediatric Psychology Consultation Program in the Department of Behavioral Psychology at Kennedy Krieger Institute is staffed with behavioral psychology specialists skilled at working with children with NDD to gradually acclimate them to the unfamiliar sensations and demands of this important procedure.

Working with caregivers, behavioral psychology staff assess the child's ability to tolerate the study, using child-friendly language and pictures. Children deemed unlikely to tolerate a sleep study may receive systematic exposure therapy to become desensitized to equipment and to learn coping skills, enabling them to tolerate the equipment and complete a sleep study. While the Kennedy Krieger Clinical Electrophysiology Laboratory offers overnight sleep studies, our team also can work with patients to prepare for studies that will be performed at other sleep laboratories. The Pediatric Psychology Consultation Program offers desensitization for a variety of other medical procedures as well, including EEG, MRI, blood draws, ultrasound, pill swallowing, and cooperation with routine medical exams.

Signs that may indicate sleep disorders:

- Difficulty falling or staying asleep
- Frequent night awakening
- Snoring
- Daytime sleepiness
- Long pauses in breathing (sleep apnea)
- Hyperactivity
- Irritability

For more information about referring a child with neurodevelopmental disorders for desensitization prior to an overnight sleep study or other medical procedure, please call our Referral Line at **443-923-9403** or email us at **FindASpecialist@KennedyKrieger.org**.

## RESEARCH STUDY FOR TYPICALLY DEVELOPING INFANTS AND YOUNG CHILDREN

Kennedy Krieger Institute is seeking typically developing infants and young children (ages 6 months to 5 years) to help us better understand the responses of young children with severe brain injuries. If enrolled in this research study, the child will be asked to look at, listen to, and touch toys. The visit will take about 60 minutes and will take place at

Kennedy Krieger Institute at the 707 N. Broadway building in Baltimore, Md. There are no significant risks or direct medical benefits for participating in this study. Each family will receive a \$25 gift card for completing testing. Contact Rachel Nicholson at **443-923-7987** or **NicholsonR@KennedyKrieger.org** to learn more.





Kennedy Krieger Institute

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## PATIENT CARE PROGRAMS & SERVICES

### Inpatient Pediatric Units

Feeding Disorders Unit  
Neurobehavioral Unit (NBU)  
Rehabilitation Unit—Brain Injury, Pain Rehabilitation,  
Post-orthopedic Surgery, and Spinal Cord Injury

### Outpatient Centers, Programs, and Services

International Adoption Clinic  
Albright Clinic  
Aquatic Therapy Program  
Assistive Technology Clinic  
Audiology Program  
Center for Autism and Related Disorders  
Barth Syndrome Clinic  
Behavior Management Clinic  
Bone Disorders Program  
Brachial Plexus Clinic  
Brain Injury Outpatient Clinics  
Brain Injury Responsiveness Program  
Phelps Center for Cerebral Palsy and  
Neurodevelopmental Medicine  
Child and Family Support Program  
Child and Family Therapy Clinic  
Community Rehabilitation Program  
Constraint-Induced and Bimanual Therapy Program  
Cranial Cervical Clinic  
Deafness-Related Evaluations Clinic  
Center for Development and Learning  
Developmental Cognitive Neurology Clinic  
Pediatric Developmental Disorders Clinic  
Down Syndrome Clinic and Research Center  
Pediatric Epilepsy and Neuropsychiatry Program  
Pediatric Feeding Disorders Program  
Fetal Alcohol Spectrum Disorders Program  
Focused Interdisciplinary Therapy Program  
Fragile X Clinic  
Healthy Lifestyles Therapy Program  
Center for Holoprosencephaly and Related Malformations  
Intrathecal Baclofen Program  
Limb Differences Clinic

Moser Center for Leukodystrophies  
Military Behavioral Health Services  
Movement Disorders Program  
Center for Genetic Muscle Disorders  
Neurobehavioral Outpatient Program  
Neurology and Developmental Medicine Program  
Neurology and Neurogenetics Clinic  
Clinical Neurophysiology Clinic and Laboratory  
Neuropsychology Outpatient Clinics  
Neurorehabilitation Concussion Clinic  
NICU Follow-up Clinic  
Nutrition Clinic  
Occupational Therapy Clinic  
Orthopedic Clinic  
Osteogenesis Imperfecta Clinic  
Pediatric Pain Rehabilitation Program  
Physical Therapy Clinic  
Pediatric Psychology and Consultation Clinic  
Psychiatric Mental Health Program  
Seating Clinic  
Sickle Cell Neurodevelopmental Clinic  
Sleep Disorders Clinic and Laboratory  
Specialized Transition Program (STP)  
Speech and Language Clinic  
Philip A. Keelty Center for Spina Bifida  
and Related Conditions  
International Center for Spinal Cord Injury  
Hunter Nelson Sturge-Weber Center  
Center for Child and Family Traumatic Stress  
Tuberous Sclerosis Clinic  
Weight Management Program

### Continuums of Care

Continuums allow patients to be seen through all stages of care, including 24-hour inpatient programs, day treatment, home- and community-based services, and outpatient programs. They include **Pediatric Feeding Disorders, Neurobehavioral Disorders, and Pediatric Rehabilitation (brain injury, pain management, post-orthopedic surgery, spinal cord injury).**

For a complete listing of all diagnoses, disorders, programs, and services, visit [KennedyKrieger.org/PatientCare](http://KennedyKrieger.org/PatientCare) or call 888-554-2080, TTY 443-923-2645, or Maryland Relay 711.