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 support 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 patient’s family to develop a comprehensive and individualized treatment plan. 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.

For your convenience and future reference, we’ve provided an overview of our 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
NEW PROGRAM: NEUROLOGICAL EVALUATIONS FOR CHILDREN WITH SICKLE CELL DISEASE

Research has shown that progressive neurological dysfunction is common in individuals with sickle cell disease. Consequently, these children require ongoing monitoring and pharmacologic treatment. Early recognition, evaluation, and treatment of neurodevelopmental disorders increases compliance with therapeutic regimens, minimizes the need for other consultation, and improves mental health outcomes for children with sickle cell disease.

The Sickle Cell Neurodevelopmental Clinic at Kennedy Krieger provides specialized neurological evaluations, developmental screenings, and educational consultations for children with sickle cell disease. The clinic will evaluate children with sickle cell disease who also have a history of developmental delay, autism spectrum disorder, language disorders, motor dysfunction, ADHD, specific learning disabilities, headaches, seizures, tics, anxiety, depression, or academic concerns.

For more information or to make a referral, please call our Physician Referral Line at 443-923-9403 or visit referrals.kennedykrieger.org.

PROGRAM SPOTLIGHT: INTENSIVE OUTPATIENT CLINIC FOR SEVERE BEHAVIORS

The Neurobehavioral Disorders Program at Kennedy Krieger Institute is one of the leading programs in the nation for intensive behavioral assessment and treatment for individuals with severe behavioral disorders and intellectual disabilities. Building off of that expertise, Kennedy Krieger has developed an intensive outpatient alternative to the inpatient setting for children and adults whose severe problem behaviors present a risk of injury to themselves or others, who have not responded to previous interventions, and who are at risk for restrictive placement.

We offer several outpatient treatment models that provide flexibility and options for patients and families, including:

- **Intensive behavioral day treatment program**—Our most effective approach, this program provides intensive behavioral therapy approximately three to five hours per day, three to five days per week for up to 12 weeks.
- **Day treatment**—This program provides behavioral assessment and treatment services in the clinic on a weekly basis for four to 12 hours per week.

Additionally, our staff remains involved in patients’ care after discharge in different capacities, depending on their needs. Generally, services are provided in the patient’s home, school, or community, and may include ongoing behavioral assessment and treatment services, phone consultations for out-of-town patients and families, or additional training for care providers to help them follow the patient’s behavioral program.

The Neurobehavioral Outpatient Clinic has recently expanded to an additional location in Columbia, Maryland, offering more convenience to families seeking treatment.

Kennedy Krieger also offers a unique 16-bed inpatient unit geared toward children and adolescents with both severe behavioral issues and developmental or intellectual disabilities. The inpatient unit is especially appropriate for helping patients who have tried other interventions and treatments that have not worked.

For more information about the neurobehavioral continuum, visit kennedykrieger.org/neurobehavioral-continuum. To make a referral, please call 443-923-9403 or visit referrals.kennedykrieger.org.

CLINICAL UPDATES: DIAGNOSIS, TREATMENT, AND SUPPORT

Online Video Helps Physicians, Parents Recognize Early Signs of Autism

Kennedy Krieger Institute and the Maryland Chapter of the American Academy of Pediatrics (AAP) developed a first-of-its-kind free online video tutorial on early autism recognition distributed to member pediatricians. Developed by autism researchers at Kennedy Krieger Institute, the goal of the tutorial is to improve recognition of the early signs of autism spectrum disorders (ASD) in one-year-olds among pediatricians, parents, and early intervention providers.

The nine-minute tutorial consists of six video clips comparing toddlers who show no signs of ASD to toddlers who show early signs of ASD. Each video is presented with a voice-over explaining how the specific behaviors exhibited by the child, as they occur on screen, are either suggestive of ASD or typical child development.

Although developed as a resource for Maryland’s pediatricians, Kennedy Krieger has also made the tutorial available to other physicians, parents, and professionals at kennedykrieger.org/AutismTutorial.

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.
Nearly One-Third of Children with Autism Also Have ADHD

- In a study of the co-occurrence of attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) in early school-age children (four to eight years old), researchers at Kennedy Krieger Institute found that nearly one-third of children with ASD also have clinically significant ADHD symptoms. Published in *Autism: The International Journal and Practice*, the study also found that children with both ASD and ADHD are significantly more impaired on measures of cognitive, social, and adaptive functioning compared to children with ASD only. Results revealed that:

  * Out of 63 children with ASD in the study, 18 (29 percent) were rated by their parents as having clinically significant symptoms of ADHD. Importantly, the age range for children in the study (four to eight) represented a younger and narrower sample than has been previously reported in published literature.
  * Early school-age children with co-occurrence of ASD and ADHD were significantly more impaired than children with only ASD on measures of cognitive and social functioning, and the ability to function in everyday situations. They were also more likely to have significant cognitive delays (61 versus 25 percent) and display more severe autism mannerisms, like stereotypic and repetitive behaviors.
  * The study findings suggest that children with the combined presence of ADHD and ASD may need different treatment methods or intensities than those with ASD only in order to achieve better outcomes.

Discovery of Gene Mutation that Causes Sturge-Weber Syndrome, Port-Wine Stain Birthmarks Offers New Hope

In the *New England Journal of Medicine*, Drs. Jonathan Pevsner and Anne Comi of Kennedy Krieger reveal their discovery of the gene mutation that causes Sturge-Weber syndrome (SWS) and port-wine birthmarks. SWS is a rare disorder affecting approximately one in 20,000 births, while port-wine birthmarks are more common, affecting approximately one million individuals in the United States. “This is a complete game changer for those with Sturge-Weber syndrome and the millions born with port-wine birthmarks,” said co-senior study author Anne Comi, MD, director of Kennedy Krieger Institute’s Hunter Nelson Sturge-Weber Center. “Now that we know the underlying genetic mutation responsible for both conditions, we’re hopeful that we can move quickly toward targeted therapies, offering families the promise of new treatments for the first time.”

With the discovery of the gene and pathway involved in SWS and port-wine stain birthmarks, researchers can now begin investigating drugs that selectively inhibit the implicated pathways. Researchers also found that this same gene is linked to uveal melanoma. The link to melanoma may also influence research and lead to new directions for the treatment of both conditions in the future.

In revealing that SWS is caused by a somatic mutation, researchers have also confirmed for the first time that Sturge-Weber is not an inherited syndrome—a meaningful insight for many parents. For more information about the details of the discovery, visit sturgeweber.kennedykrieger.org.

New Neurorehabilitation Research, Treatment, and Trends Newsletter

In each issue of Kennedy Krieger’s *Rehabilitation Updates* newsletter, we feature one of the Institute’s neurorehabilitation programs, and share how our innovative therapies, equipment, and technologies are enhancing patient outcomes. We also include updates on clinical research and notes about staff and programs. To receive your copy of *Rehabilitation Updates*, visit kennedykrieger.org/patient-care/health-care-professionals.

Online Referral Form for Psychological and Neuropsychological Assessments

The Department of Neuropsychology at Kennedy Krieger is now offering the convenience of an online referral form for patients with a range of neurological, developmental, learning, and behavioral concerns. The online form will accelerate the appointment scheduling process and provide a level of convenience for physicians and their staff. A referral pad is also available for physicians who prefer to complete a hard copy of the form to give to patients and families. Neuropsychological evaluations are offered at two Maryland locations: Baltimore and Columbia. Online referrals will soon be available for other services at Kennedy Krieger.

Visit neuropsychologyintake.kennedykrieger.org or call 443-923-9403 to refer a patient or request a referral pad.
PATIENT CARE PROGRAMS & SERVICES

Inpatient Pediatric Programs
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
Botulinum Toxin Treatment Program
Brachial Plexus Clinic
Interdisciplinary Brain Injury Clinic
Brain Injury 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
Family Center
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
Moser Center for Leukodystrophies*

Limb Difference Clinic
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 Neuropsychology Clinic
Clinical Neuropsychology Laboratory
Neuropsychology and Developmental 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
Psychiatry Clinic
Pediatric Psychology and Consultation Clinic
Pediatric Rehabilitation Clinic
Seating Clinic
Sickle Cell Neurodevelopmental Clinic*
Sleep Disorders Clinic and Laboratory
Social Work Outpatient Mental Health Clinic
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
Tuberous Sclerosis Clinic

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).

*Indicates new programs, clinics, and services.

For a complete listing of all diagnoses, disorders, programs, and services, visit kennedykrieger.org/patientcare or call 888-554-2080, TTY 443-923-2645, or Maryland Relay 711.