

Neurorehabilitation Updates

Collaborative care, innovative approaches, and research-driven therapies to help patients get back to their lives.

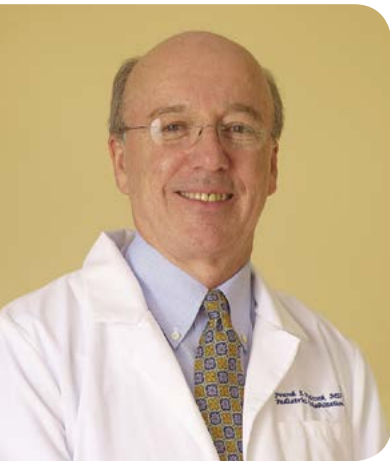


Kennedy Krieger Institute
UNLOCKING POTENTIAL

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A Word from the Director

Frank S. Pidcock, MD, Vice President of Rehabilitation at Kennedy Krieger Institute, Director of the Pediatric Rehabilitation Division in the Department of Physical Medicine & Rehabilitation, Johns Hopkins Hospital



Kennedy Krieger Institute provides a wide range of services for patients with cerebral palsy, including innovative diagnostic tools, unique approaches to therapy, and transitional programs that address the needs of patients as they age. In this issue of *Neurorehabilitation Updates*, we highlight some of these exciting interventions and share the story of one of our young patients who has benefited from our collaborative care.

The care of children with cerebral palsy can be divided into three phases. The first is accurate and timely diagnosis. A team of geneticists and neurodevelopmental specialists at the Institute is shedding light on the causes of cerebral palsy

by analyzing genetic sequences using exome analysis. Dr. Ali Fatemi, Director of Neurogenetics, believes that exome sequencing can determine a genetic diagnosis in at least 40% of children with a neurodevelopmental disability of unknown cause.

Once a diagnosis is made, a carefully planned approach to therapy is essential. Ideally, therapy begins before age two to take advantage of the inherent neuronal plasticity of the developing brain. Understanding the best way to link essential, ongoing interventions, including splinting and bracing, with well-timed intensive “boost” therapy is key to managing the effects of cerebral palsy.

Maximizing quality of life is the third phase in caring for children with cerebral palsy. The Phelps Center for Cerebral Palsy at Kennedy Krieger, directed by Alexander Hoon, MD, provides a wide range of conferences and seminars for families of individuals with cerebral palsy, in partnership with Kinetic Connections.

At Kennedy Krieger, we are in a unique position to care for patients with cerebral palsy across their life span, with effective interventions and individualized, meaningful support services. Read on to learn more. If you have any questions or would like to learn more about any of our services, please call our **Physician Referral Line at 443-923-9403** or visit rehabilitation.kennedykrieger.org.

Rehabilitation Specialty Programs at Kennedy Krieger Institute

Kennedy Krieger Institute has a wide variety of rehabilitation programs to meet the needs of patients at all levels. For a complete listing, please visit rehabilitation.kennedykrieger.org.

Pediatric Inpatient Rehabilitation Program

- Brain injury
- Medical rehabilitation
- Pain rehabilitation
- Post-orthopedic surgery
- Spinal cord injury

Outpatient Rehabilitation Programs

- Brachial Plexus Clinic
- Brain Injury Programs:
 - Brain Injury Early Assessment
 - Brain Injury Responsiveness Program
 - Interdisciplinary Brain Injury Clinic
 - Neurorehabilitation Concussion Clinic
- Community Rehabilitation Program
- Constraint-induced and Bimanual Therapy Program
- Cranial Cervical Clinic
- Focused Interdisciplinary Therapy Program
- International Center for Spinal Cord Injury
- Limb Differences Clinic
- Orthopedics Clinic
- Pediatric Pain Rehabilitation Clinic
- Phelps Center for Cerebral Palsy and Neurodevelopmental Medicine
- Philip A. Keelty Center for Spina Bifida and Related Conditions
- Physical Medicine and Neurorehabilitation Clinic
- Specialized Transition Program Day Hospital

Related Services and Clinics

- Aquatic Therapy Program
- Assistive Technology Clinic
- Audiology Clinic
- Behavioral Psychology Program
- Movement Disorder Clinics
- Neuropsychology Outpatient Clinics
- Nutrition and Weight Management Clinic
- Occupational Therapy Clinic
- Pediatric Psychology Clinic
- Physical Therapy Clinic
- Seating Clinic
- Speech and Language Clinic

For Patients with Cerebral Palsy, Collaborative Care is Key

Children with cerebral palsy require care from multiple specialists throughout childhood, as their needs change during growth. "Initial care should focus on making an accurate diagnosis and starting developmental-based therapies," says Frank Pidcock, MD, director of rehabilitation at Kennedy Krieger. "As children get older, the focus expands to include the management of orthopedic complications."

Kennedy Krieger offers comprehensive and collaborative care for these patients at every stage, drawing on specialists from many different disciplines. Therapists and physicians see patients in the same area and often co-schedule their appointments to promote collaboration. "Working together naturally lends itself to sharing ideas about prescribing the right orthotics or discussing the types of therapies that would be best for a particular child," explains Pidcock.

One patient who has benefited from this collaborative approach is 10-year-old Elijah, who has been a patient at Kennedy Krieger since infancy. Up until last year, the team was able to prevent orthopedic complications for Elijah through medication, splints, and braces. But the combination of growth and the pull of spastic muscles on his hip joint finally resulted in hip subluxation last spring. Dr. Pidcock and orthopedic surgeon Ranjit Varghese, MD, decided it was time for corrective surgery.



Elijah and his parents meet with their care team: physical therapist Heather McLean, physiatrist Frank Pidcock, and orthopedic surgeon Ranjit Varghese.

"Working together naturally lends itself to sharing ideas about prescribing the right orthotics or discussing the types of therapies that would be best for a particular child."

—Frank Pidcock, MD, Director of Rehabilitation

(below) Physical therapist Heather McLean works with Elijah on balance.



(above) State-of-the-art gait trainers and other adaptive equipment help patients improve functional mobility, even if they are unable to walk.

Following surgery, Elijah was admitted to the inpatient rehabilitation unit at Kennedy Krieger, where an experienced team of therapists, nurses, child life specialists, and physicians worked together to achieve an optimal outcome from surgery. "The post-surgical period is critical," explains Pidcock. "If the proper therapy after surgery does not occur, the benefits from the operation can be lost."

Elijah experienced muscle spasms early on in his inpatient rehabilitation hospitalization after surgery. His therapy team worked closely with the medical team to adjust the dose of medication to treat the spasms, while not interfering with his alertness and ability to benefit from therapies.

With family input, the therapists developed a program tailored to Elijah's needs. His initial therapy goals included learning to tolerate movement and different positions after being immobilized in a cast following surgery. His therapists worked with him on sitting balance, weight bearing, transfers, and walking in a gait trainer, which he would not have attempted before his surgery.

The team also worked with Elijah's mom, Gloria, on caregiver training, so he could continue exercises at home. Gloria is pleased with how much progress Elijah made and says her son is more confident and independent now. "He used to be so tight in his legs," she says. "His movements are more controlled now, and he can pull himself up from lying on his side to sitting, which is great. It's one of his biggest milestones."

Elijah will continue his care at Kennedy Krieger, where his team of specialists will be ready to help him through the next step of his journey.

To learn more about cerebral palsy programs at Kennedy Krieger Institute, visit kennedykrieger.org/cerebral-palsy.

From Bench to Bedside

Kennedy Krieger's clinicians and researchers are leaders in the worldwide effort to prevent and treat disorders of the brain, spinal cord, and musculoskeletal system. Our investigators continue to break new ground with innovative imaging technology, investigate critical areas, and develop new treatment models and therapies. Selected recent research on cerebral palsy-related topics includes:

Faria, A.V., Hoon, A., Stashinko, E., Li, X., Jiang, H., Mashayekh, A., Akhter, K., Hsu, J., Oishi, K., Zhang, J., Miller, M.I., van Zijl, P.C., Mori, S. Quantitative Analysis of Brain Pathology Based on MRI and Brain Atlases – Applications for Cerebral Palsy. *Neuroimage*. 2011 Feb 1; 54(3):1854-61. Epub 2010 Nov 5. PMID: 20920589

Garcia Reidy, T., Naber, E., & Tsai, T. (2013). Chapter 12. Novel and Complementary Therapy Strategies: Critical Issues and Opportunities for Combining with Pediatric CIMT. In *Handbook of Pediatric Constraint-Induced Movement Therapy (CIMT): A Guide for Occupational Therapy and Health Care Clinicians, Researchers, and Educators*. Edited by S. Deluca, P. Coker-Bolt & S. Ramey. AOTA Press. Bethesda, MD

Garcia Reidy, T., Naber E., et al. (2012). Outcomes of a Clinic-Based Pediatric Constraint Induced-Movement Therapy Program. *Physical & Occupational Therapy in Pediatrics*, 32(4):355–367.

Hoon, A.H., & Stashinko, E. (Accepted for Publication 05SEP2014). Self-reported similarities in quality of life in adolescents with and without cerebral palsy. *Lancet* (editorial).

Pidcock, F.S., Garcia, T., Travato, M., Schultz, S.C., & Brady, K. (2009) Pediatric Constraint-Induced Movement Therapy: A Promising Intervention for Childhood Hemiparesis. *Topics in Stroke Rehabilitation*.

Reidy, T., Allison, K., Naber, E., Boyle, M., & Pidcock, F. (2011) Comparing changes in bimanual skills with speech production gains following constraint-induced movement therapy in children. American Academy of Cerebral Palsy and Developmental Medicine 65th Annual Meeting, Las Vegas, NV.

Grants:

2014. Developmental Trajectories of Impairments, Associated Health Conditions, and Participation of Children with Cerebral Palsy. Direct Cost: \$5,000. Sponsor: The Canadian Institutes for Health Research, MOP 119276. Site PI: Frank Pidcock, MD.

2014-16. Quantitative mapping of the basal ganglia and related structures in children with dyskinetic cerebral palsy. Alexander H. Hoon, PI., E. Stashinko, H. Gwynn (Co-investigators).

Cerebral Palsy International Research Foundation, Cerebral Palsy Alliance of Australia (\$100,000).

For more information about research, studies and clinical trials at Kennedy Krieger Institute, please visit kennedykrieger.org/research.

Managing Abnormal Muscle Tone

Building on its expertise of treating children with developmental disorders like cerebral palsy or acquired brain injury, Kennedy Krieger's unique, interdisciplinary spasticity evaluation program addresses the needs of children with abnormal muscle tone. The clinic team consists of specialists from pediatric rehabilitation, orthopedics, neurosurgery, neurodevelopmental pediatrics, physical therapy, and occupational therapy.

Each patient receives an initial assessment that includes diagnostic tests and detailed measurements of position and function, and a comprehensive treatment plan to manage spasticity. Therapeutic interventions include selective dorsal rhizotomy, botulinum toxin A, baclofen pumps, chemodenerivation, orthopedic procedures, oral medications, and orthotics.

Kennedy Krieger is home to one of only a few clinics in the country that offers all of these treatment options combined with comprehensive inpatient or outpatient rehabilitation to manage abnormal muscle tone. Evaluations and treatment recommendations are available by calling **443-923-9403** or emailing findaspecialist@kennedykrieger.org.

Institute Receives Highest Level of Accreditation from CARF International

Kennedy Krieger's receipt of a three-year accreditation from the Commission on Accreditation of Rehabilitation Facilities (CARF) shows the Institute's conformance to CARF's highest standards. In order to receive the designation, an organization must undergo a rigorous peer-review process and demonstrate commitment to programs and services that are measurable, accountable, and of the highest quality to a team of surveyors who visit each site.

The following programs received accreditation:

- Pediatric Rehabilitation Unit
- Neurobehavioral Unit
- Pediatric Feeding Disorders Unit
- International Center for Spinal Cord Injury (pediatric inpatient and outpatient)
- Specialized Transition Program
- Community Rehabilitation Program



Kennedy Krieger Institute

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Institute Hosts International Hand Assessment Event

Practitioners in the fields of occupational and physical therapy came from all over the world in September to attend the Assisting Hand Assessment (AHA) workshop hosted by the Kennedy Krieger Constraint-induced and Bimanual Therapy Program. This international workshop was held in only two U.S. locations in 2014, and was the first of its kind in the Baltimore area. Lena Krumlinde-Sundholm, OT, PhD, came from the Karolinska Institute in Stockholm to teach the certification course.

The AHA is an evaluative tool to measure how effectively children with unilateral hand dysfunction use their involved hand collaboratively with their well-functioning hand to perform bimanual tasks. For the child, the AHA is a brief, enjoyable, semi-structured play session using a test-kit of selected toys requiring bimanual use. The AHA is then scored from structured video recordings of the observable performance skills during this play.

New App Developed for Individuals with Cerebral Palsy

Some individuals with cerebral palsy and other disabilities have difficulty advocating for themselves and having their unique needs met during day-to-day activities or medical emergencies, especially if they have communication challenges. To address this concern, a team of physicians and therapists at Kennedy Krieger and Johns Hopkins created an app called Important Information About Me (IIAM).

IIAM is one of only a few iPad apps that provide the disability world with the tools to communicate their individual needs. Beyond medical history, IIAM offers novel ways to express coping mechanisms, behavior, feeding, communication, and self-perception of disability. The app features video and picture embedment and medication notifications, providing users with a better understanding of the individual's baseline abilities and needs.

For more information about how to access the app, please visit kennedykrieger.org/iiam-app.

Short-term Intensive Therapy Program for Cerebral Palsy

For children and young adults with cerebral palsy and other neurodevelopmental conditions, the **Focused Interdisciplinary Therapy Program** at Kennedy Krieger uses an interdisciplinary approach in which physical and occupational therapists, speech-language pathologists, educators, and neuropsychologists work together to implement a short, intensive program individualized for each patient. The specific frequency, duration, and choice of therapies vary according to the age, abilities, and goals of each individual, but typically, patients receive therapy services three to six hours per day, five days a week, for four to six weeks. The program uses a variety of therapeutic equipment to assist patients in reaching their goals, including robotics, electrical stimulation, gait trainers, augmentative communication devices, and other innovative technologies. Patients and families have found this intensive boost of therapy successful—92 percent of patients who recently participated in this program met or exceeded goals in areas such as mobility, strength, endurance, and increased independence in the home and community.

For more information or to make a referral, call 443-923-4587 or email mauldin@kennedykrieger.org.