

Clinical Connection

News, Updates and Support for Healthcare Professionals



Kennedy Krieger Institute

REHABILITATION • DEVELOPMENTAL MEDICINE • BEHAVIORAL THERAPIES



Dear Friend,

I hope this letter finds you and your colleagues and loved ones safe and well.

As I write to you, I'm acutely aware that there hasn't been a period in my lifetime that compares with what we are all facing due to the COVID-19 pandemic. To say these are unprecedented times is not an exaggeration.

My Kennedy Krieger colleagues, as well as the culture here at the Institute, are truly remarkable. That description was already apt before the pandemic hit, but during times of adversity, true character and culture are revealed.

We responded, and are responding, to the pandemic with one singular focus: continuing to provide excellent care and education to our patients and students, and their families. I'm so very proud of our Kennedy Krieger community for all we've accomplished in the past several months—including collaborating with committed professionals like you and expanding our telehealth and tele-education services to well more than 5,000 appointments and sessions a week—to ensure children and families get the care, education and support they need.

Our collective expertise and services will be even more crucial in the post-pandemic world. With your support, we will remain strong and move forward with new tools and approaches to ensure every child and family who need us may access the care and education we provide.

I hope you are inspired by the stories told in this modified edition of *Potential* magazine. We think these individuals and families are heroic, as are you and your colleagues, for your resilience and resolve to continue to provide important care during these difficult times.

Thank you for all you do for your patients and their families. We truly could not do what we do without you.

Stay safe and be well,

Bradley L. Schlaggar, MD, PhD
President and CEO

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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 **[KennedyKrieger.org/Referrals](https://www.kennedykrieger.org/Referrals)** for information and resources for physicians and healthcare professionals.

For general information, visit **[KennedyKrieger.org](https://www.kennedykrieger.org)** or call **1-888-554-2080**.

OUR CULTURE OF CARE

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. © 2020 Kennedy Krieger Institute 08/2020

Telehealth Ensures Continuous Specialty Care for Patients

At the start of the COVID-19 pandemic, Kennedy Krieger quickly shifted the majority of outpatient appointments to telehealth.

As states and countries enacted stay-at-home orders this past spring to “flatten the curve” of the COVID-19 pandemic, medical providers around the world turned to telehealth to provide ongoing care to patients in need of their services.



For Kennedy Krieger Institute, that move to telehealth was a seamless transition, as the Institute has been offering telehealth to patients for several years. At the start of the pandemic, the Institute’s telehealth model was quickly adopted by programs, clinics, departments and centers across the Institute.

Telehealth’s growth at Kennedy Krieger was swift: The week

of March 9, Kennedy Krieger conducted 4,773 in-person appointments and 12 telehealth appointments. One month later, weekly telehealth appointments numbered more than 5,000, while in-person appointments were not quite 300. Since then, in-person services have increased, while telehealth services have remained high: In the last week of July, Kennedy Krieger conducted 4,587 telehealth appointments and 534 in-person appointments.

“It’s a whole new treatment model, and we coalesced around it in just a couple of weeks,” says **Deepa Menon, MBBS**, assistant medical director for the Institute’s Center for Autism and Related Disorders (CARD), which offered occasional telehealth appointments before the pandemic.

“I’d always wanted to expand telehealth to other fields, to decrease health disparities among patients who cannot easily visit us in person,” Dr. Menon says. “We’d been talking about it for many years, and this was the opportune time to try it out on a larger scale.”

What makes it work, Dr. Menon says, is that “we keep patients and families in the center of all we do.” Kennedy Krieger’s goal during the pandemic—and beyond—is that every child and family who need its expertise will be able to access it. Telehealth and patient-centered care make that goal achievable.

“We have had to find new ways to get patient information and to evaluate a child,” adds **Paul Lipkin, MD**, the Institute’s director of medical outpatient services. “But at the same time, we’ve also developed a more personal experience with families, as we ‘enter’ their home and have a personal conversation with them regarding their adjustments during this difficult time.”

One of the challenges of providing medical care to Kennedy Krieger’s patients and students via telehealth is the interdisciplinary nature of that care.

The Institute’s Infant Neurodevelopment Center, for example, takes a team approach in evaluating infants and children with perinatal brain injuries. The center developed a virtual conference room model, in which different “exam rooms” on Zoom, a videoconferencing platform, are organized through a virtual “conference room.” This allows team members to perform a virtual, interdisciplinary evaluation of a patient and have a place to discuss the evaluation in real time, explains developmental neurologist **Joanna Burton, MD, PhD**, a co-director of the center.

Initially, Dr. Burton and her colleagues didn’t think they would be able to make diagnoses during telehealth appointments. “But on the first day of telehealth, we broke that rule, with three cerebral palsy diagnoses,” she says.

“The spirit behind early diagnosis is letting families know what we know when we know it. If there’s an intervention that allows children better functioning, we need to make sure they get it,” Dr. Burton explains. “On that first day of telehealth, as parents evaluated their child’s range of motion, you could see in their faces as they recognized asymmetries in their child’s muscle tone. It would have done them a disservice not to confirm the diagnosis.”

Another challenge presented by telehealth appointments has been that not everyone has the necessary technology. For families without a computer, tablet or smartphone, Kennedy Krieger has loaned tablets and other equipment, or conducts appointments over the telephone.

Kennedy Krieger leaders note that this pandemic has accelerated a change in the landscape of patient care, and that virtual appointments combined with in-person appointments will likely be the way of the future.



New Clinics for Treating Neurological Disorders and Injuries

Kennedy Krieger Institute is excited to announce the addition of three clinical programs designed to meet the needs of children, and their families, with neurological disorders and injuries. They are:

- **Pediatric Postural Orthostatic Tachycardia Syndrome (POTS) Clinic:** This clinic provides expert diagnostic services and treatment for children and adolescents with POTS. Treatment often includes both pharmacological and nonpharmacological interventions. Early intervention with physical and occupational therapies, as well as behavioral psychology therapies for managing and coping with the disorder, are also key to improved outcomes.
- **Ataxia and Cerebellar Disorders Clinic:** This clinic provides expert diagnostic services and treatment for ataxia and cerebellar disorders for children under the age of 16. The clinic's interdisciplinary team treats children who are newly diagnosed and those who have had the disorder for a period of time, as well as children and teens for whom ataxia is suspected and an accurate diagnosis is needed.
- **Tourette Syndrome Center of Excellence at Kennedy Krieger Institute and Johns Hopkins Medicine:** This center is a collaboration that leverages the expertise of both organizations to provide the best outcomes for children and adults with Tourette syndrome and other tic disorders. The center offers interdisciplinary medical evaluations and the most recent treatment options from leading experts in the fields of pediatric and adult neurology, psychiatry and neurophysiology. The center has been recognized by the Tourette Association of America as a Center of Excellence.



Kennedy Krieger Inpatient Units Continue to Treat Medically Fragile Children

While Kennedy Krieger Institute transitioned the majority of its outpatient appointments to telehealth at the start of the COVID-19 pandemic, the Institute's inpatient hospital has remained open, serving patients and families in need of Kennedy Krieger's specialty inpatient care and rehabilitation. The Institute has implemented restrictions on visitation and other protocols to ensure the safety of staff members, patients and families. The hospital continues to admit patients with the following conditions and disorders requiring inpatient care:

- Brain injuries
- Chronic pain
- Complex medical conditions
- Feeding disorders
- Postorthopedic surgery rehabilitation
- Severe behavioral disorders
- Spinal cord injuries

Email FindASpecialist@KennedyKrieger.org to speak with an intake specialist about an inpatient admission or to get additional information.

Email FindASpecialist@KennedyKrieger.org or call **443-923-9403** to learn more or to make an appointment at any of these clinics, or with any other Kennedy Krieger clinical program.



Kennedy Krieger Institute

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PATIENT CARE PROGRAMS & SERVICES

Specialty Pediatric Hospital

Feeding Disorders
Neurobehavioral Unit (NBU)
Rehabilitation Unit—brain injury, complex medical, pain management, postorthopedic surgery and spinal cord injury

Outpatient Centers, Programs and Services

International Adoption Clinic
Aquatic Therapy Program
Assistive Technology Clinic
Ataxia and Cerebellar Disorders Clinic
Audiology Clinic
Center for Autism and Related Disorders
Barth Syndrome Clinic
Behavior Management Clinic
Bone Disorders Program
Brachial Plexus Clinic
Center for Brain Injury Recovery
Phelps Center for Cerebral Palsy and Neurodevelopmental Medicine
Child and Family Support Center
Child and Family Therapy Clinic
Community Rehabilitation Program
Concussion Clinic
Constraint Induced and Bimanual Therapy Program
Pediatric Post-COVID-19 Rehabilitation Clinic
Cranial Cervical Clinic
Deafness-Related Evaluations Clinic
Center for Development and Learning
Pediatric Developmental Disabilities Clinic
Down Syndrome Clinic and Research Center
Epilepsy Clinic
Pediatric Feeding Disorders Program
Focused Interdisciplinary Therapy Program
Fragile X Clinic
Healthy Lifestyles Therapy Program
Infant Neurodevelopment Center
Moser Center for Leukodystrophies

Limb Differences Clinic
Military Behavioral Health Services
Center for Genetic Muscle Disorders
Neurobehavioral Unit Outpatient Clinic
Neurology and Neurogenetics Clinic
Clinical Neurophysiology Clinic and Laboratory
Neuropsychiatry in Epilepsy Program
Neuropsychology Department Outpatient Clinics
Specialized Transition Program Neurorehabilitation Day Hospital
Nutrition Clinic
Occupational Therapy Clinic
Orthopedic Clinic
Osteogenesis Imperfecta Clinic
Pediatric Pain Rehabilitation Program
Physical Therapy Clinic
Pediatric Postural Orthostatic Tachycardia Syndrome (POTS) Clinic
Psychiatric Mental Health Program
Pediatric Psychology Consultation Program
Rehabilitation Clinic
Seating Clinic
Sickle Cell Neurodevelopmental Clinic
Sleep Disorders Clinic and Lab
Speech and Language Outpatient Clinic
Philip A. Keelty Center for Spina Bifida and Related Conditions
International Center for Spinal Cord Injury
Hunter Nelson Sturge-Weber Syndrome Center
Tourette Syndrome Center of Excellence at Kennedy Krieger Institute and Johns Hopkins Medicine
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 in 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, complex medical, pain management, postorthopedic surgery and spinal cord injury).**

For a complete list of all diagnoses, disorders, programs and services, visit [KennedyKrieger.org/PatientCare](https://www.kennedykrieger.org/PatientCare) or call **888-554-2080**. TTY users, please contact us at **443-923-2645**, or dial **711** to make a Maryland Relay call.