

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've responded to the pandemic with one singular focus: continuing to provide excellent care and education to our patients and students. Part of our response has been to create the interdisciplinary Pediatric Post-COVID-19 Rehabilitation Clinic to assess and treat children and teens who have recovered from COVID-19, but who may still have lingering neurologic and other effects. I'm so proud of all we've accomplished this year, including collaborating with committed professionals like you, to ensure children get the care 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.

As you know, the pandemic has sharply revealed our nation's long-standing inequities in healthcare. In this issue of *Potential* magazine, we take a critical look at the importance of equity, diversity and inclusion in healthcare, as well as in education, research, advocacy and employment.

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,

A handwritten signature in black ink that reads "Brad".

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 both telehealth and on-site, in-person appointments for patients and families.

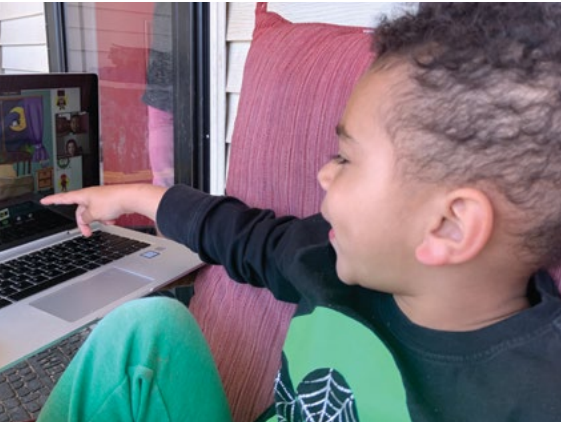
Call **443-923-9403** to reach our Physician Referral Line, or visit **[KennedyKrieger.org/Referrals](https://www.kennedykrieger.org/Referrals)** for information and resources for physicians and healthcare professionals.

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 employees, trainees, and patients and students, and their families. At Kennedy Krieger, we ground our care, services, training and research in treating others with respect and civility. We respect the cultural identity of every person. Kennedy Krieger Institute does not discriminate against people based on, but not limited to, perceived or actual race, color, ethnicity, national origin, age, language spoken, accent, marital status, veteran or military status, immigration status, disability, religion, pregnancy status, sex, sexual orientation, or gender identity or expression. We strive for equitable care for all individuals for whom we provide services, training, education and research participation. We encourage employees, trainees, and patients and students, and their families, to become active partners in the services provided by asking questions, seeking resources and advocating for their needs.

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Patient Experience With Telehealth

Kennedy Krieger Institute greatly increased its telehealth services in March 2020 in response to the COVID-19 pandemic, as did many other healthcare providers. The Institute leveraged its existing small telehealth program to help its patients access therapeutic and developmental services. More than 80 clinical programs at Kennedy Krieger now offer services via telehealth.

To ensure standards of clinical excellence are maintained when using telehealth, we surveyed parents to gain insights about the ease and effectiveness of their child's telehealth appointments. The survey, the Patient Experience Questionnaire, received almost 2,000 parent responses.

Here are key takeaways from the survey:

- Nearly 95% of parents told us they were satisfied with their child's telehealth appointment and thought the telehealth technology was easy to use.
- Following their child's telehealth appointment, the majority of parents told us they felt confident in 1) their understanding of their child's condition and 2) their ability to advocate for their child's needs.
- Just over 75% of parents told us they would use telehealth services again, even if an on-site appointment was an option.

While we found the positive responses encouraging, we also wanted to know what improvements could be made. One of the biggest challenges with telehealth is that even though most parents thought the telehealth system was easy to use, there were some parents who experienced difficulty with the appointments due to an inconsistent WiFi connection, especially when other family members were using the home WiFi for personal use and/or school. To help these families, we took several steps, including distributing iPads and portable WiFi boosters to about 250 families.

We received the most positive ratings of telehealth appointments from parents of school-aged children, teenagers and young adults. In general, this group of parents was very interested in having their children continue to receive services via telehealth even after on-site appointments were available.

The feedback we received from parents of younger children (ages 5 and under), however, was divided. While some parents of young children were enthusiastic about telehealth, others reported that their children had difficulty paying attention and engaging with their Kennedy Krieger provider using telehealth.

To help these families, we initiated a comprehensive safety program to make our on-site patient areas as safe as possible, even during the pandemic. Once these safety measures were in place and the state of Maryland had given us permission to bring patients on-site, we were able to resume on-site services on a very limited basis. Because of the feedback we received from parents, children under age 5 were among the first scheduled to be seen on-site.

Then, we started using a blended model of care for some of these patients. The blended model includes a combination of on-site and telehealth appointments. Using a blended model has allowed Kennedy Krieger providers to meet with and assess some younger children on-site and continue their treatment using telehealth.

We continue to monitor patient experience data for telehealth and tweak processes to meet the needs of our patients and their families.

Visit [KennedyKrieger.org/Telehealth](https://www.kennedykrieger.org/Telehealth) to learn more about our telehealth services for your patients.

BY THE NUMBERS

Between March and October 2020:

145,960 telehealth appointments took place

18,791 telehealth patients were seen

4,000+ telehealth appointments took place each week

689 Kennedy Krieger clinicians provided services via telehealth

Decline in Referrals of Children Under Age 5

Since the start of the COVID-19 pandemic, the developmental pediatricians and clinicians who see Kennedy Krieger Institute's youngest patients have seen a sharp reduction in referrals of children under the age of 5 for evaluation of developmental delays. This reduction is extremely concerning, because early assessment and identification of developmental delays, and the causes of those delays, are essential for proper intervention to ensure a child's future health and development.

The pandemic has affected the ways in which parents receive input about their child's development:

- Patient visits to pediatricians have been reduced or delayed.
- Preschool programs are closed or are virtual, so education professionals are not observing or interacting with children in the same ways as they did before the pandemic.
- Playtime with other children and visits to playgrounds are limited or not happening, so parents are less likely to observe their child in relation to their peers.

Especially concerning is the fact that children are now coming to their first appointment for evaluation about six months later than they would have before the pandemic, according to Joanna Burton, MD, PhD, a developmental pediatrician at Kennedy Krieger. Additionally, some of the more subtle cues for developmental delays can be easily missed in virtual well-baby visits. As a result, we implemented strict COVID-19 safety measures that allow us to see children under the age of 5 on-site, in person, for thorough evaluations.

For more information about scheduling a developmental screening for a patient, please send an email to FindASpecialist@KennedyKrieger.org or call **443-923-9403**.





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.