

potential

A publication of Kennedy Krieger Institute Summer 2021

A World of Difference How a New Diagnosis Changed Sam's Life

Amazing Recovery

Daily Therapies, 24/7 Care and a
Large Dose of "Awesomeness"

Beyond Expectations

Flourishing at Kennedy Krieger's
Fairmount Elementary School

Life-Changing Opportunity

A Special Benefit for Employees
Helps Them Realize Their Dreams



Kennedy Krieger Institute



Greetings From Our President

Dear Friend of Kennedy Krieger,

Much in our lives has changed as a result of the COVID-19 pandemic. I'm pleased to share, however, that *Potential* magazine continues to bring you uplifting stories and news of the remarkable progress that our patients, students, faculty and staff are making.

In the pages that follow, you can read about some of the collaborative milestones, tireless research and personal triumphs happening at Kennedy Krieger Institute, including the amazing progress made by Sam, featured on the cover, after his surprising epilepsy diagnosis.

There's not enough room here to highlight all of the noteworthy news that's come out of the Institute over the past few months, but here's a quick summary of recent news coverage of Kennedy Krieger:

- Chief Science Officer Dr. Amy Bastian was recently awarded a \$4.7-million grant to research how brain injuries affect movement learning: [KennedyKrieger.org/MovementLearningStudy](https://www.kennedykrieger.org/MovementLearningStudy)
- Our Pediatric Post-COVID-19 Rehabilitation Clinic continues to help children recover from the long-term effects of COVID-19: [KennedyKrieger.org/NBC_LongHaulChildrensClinic](https://www.kennedykrieger.org/NBC_LongHaulChildrensClinic)
- Stephanie King, director of our Therapeutic Foster Care program, spoke with the University of Maryland's Capital News Service about how the pandemic has created new challenges for children in foster care, and their families: [KennedyKrieger.org/CNS_FosterCare](https://www.kennedykrieger.org/CNS_FosterCare)

For these stories and much more news, visit [KennedyKrieger.org/News](https://www.kennedykrieger.org/News) or use this QR code:



I hope you enjoy this issue of *Potential*, and that you have a safe and happy rest of your summer. And as always, thank you so much for your support for our work.

Bradley L. Schlaggar, MD, PhD
President and CEO
Kennedy Krieger Institute

On the cover: Sam receives care for epilepsy and autism spectrum disorder at Kennedy Krieger Institute. Turn to page 8 to read more about Sam.

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for more inspiring stories, news and updates.

A Life-Changing Opportunity

Kennedy Krieger's tuition reimbursement benefit allowed Patrick Oliver to become a respiratory therapist. Now he's giving back, encouraging others to follow their dreams, too. *By Christianna McCausland*

Patrick Oliver has always loved working with young people. When he was 21, he took a job as a technician for Kennedy Krieger Institute's International Center for Spinal Cord Injury. He enjoyed offering hands-on assistance to the center's physical and occupational therapists, and they noticed his potential.

"The center's staff members were always pushing me to try to do something else like physical therapy, and they told me about the tuition reimbursement that Kennedy Krieger offers to employees, so I could go back to school," he recalls. He'd been wanting to return to school, but didn't know what he wanted to study. "Then I took an interest in the respiratory therapists who came to the gym every day, and I would talk with them about the work they did."

He applied to the competitive Respiratory Care Therapy program at the Community College of Baltimore County, Essex, and was accepted. His tuition was fully covered by Kennedy Krieger's tuition reimbursement benefit. The Institute was also flexible with his hours, allowing him to balance his job with school.



"While he was in school, you could see how supported he felt and how he appreciated that we were all pulling for him," says physical therapist Dr. Rachel Mertins, who worked with Oliver at the spinal cord injury center.

"Kennedy Krieger opened my eyes and gave me the opportunity to be more," he says, noting that he also took inspiration from his work. "At Kennedy Krieger, I saw young people my own age who looked like me but who were in situations worse

than mine—accidents, gunshot wounds, gang violence—they had injuries, and many of them had a lot of issues, but they turned their lives around at Kennedy Krieger."

Today, Oliver is a respiratory therapist at the Johns Hopkins Children's Center. He's also studying business and finance at Towson University, with an eye toward eventually moving into hospital administration.

Oliver often pays forward the opportunity he was given, encouraging others to seek employment at Kennedy Krieger and to make use of the tuition reimbursement benefit. When Mertins asked him to speak to Mentoring Male Teens in the Hood (MMTH), an organization with which she's volunteered for more than 10 years, he seized the chance. Part of MMTH's mission is to expose young men to role models and career paths.

"I've seen how the kids respond more to those they can relate to," Mertins says. "Patrick is from Baltimore, and he was able to talk about not knowing exactly what he wanted to do and how his career grew—he was so inspiring."

Initially, Oliver got a lot of blank stares from the kids—they didn't know what a respiratory therapist was. But once he explained what he does, they were immediately engaged.

"I told them my story and to not get frustrated," Oliver says.

"These kids want to be something, and I let them know they have chances in life."



"The tuition reimbursement benefit changes lives," Mertins says, "and it needs to be shared with the world. We make a difference here with our patients, but we also make a difference in the lives of our staff members, too."

Visit [KennedyKrieger.org/Benefits](https://www.KennedyKrieger.org/Benefits) for more information on tuition reimbursement and other benefits available to employees of the Institute.

Kennedy Krieger Institute

'I've Got This!'



Creed has flourished at the Institute's Fairmount school. He's social, confident, eager to learn and always ready to cheer on his classmates.

Michelle will never forget the day she and her husband finally found the best school for their son Creed.

It was in 2016, and they'd already visited several schools for students with special needs, but none had felt just right for Creed, now 12, who has autism spectrum disorder. The last school on the list was Kennedy Krieger Institute's Fairmount Campus school, in downtown Baltimore. It was a little far from their home near Annapolis, but wanting to be thorough, they made an appointment to take a tour.

"Walking into the school was like taking a breath of fresh air," Michelle recalls. "It had classrooms, a gym, a library—all the things you'd hope your kid would be able to have access to."

School staff members led Michelle and her husband through specially designed therapy and sensory rooms. "They showed us how they'd meet all of his needs, and talked about how they'd help him in different situations, while still making us feel really comfortable about all of those things," Michelle says.



Creed and his teacher, Chelsey Bush

“When the tour ended, my husband and I looked at each other and said, ‘Wow, this is it!’ There were no other considerations. This was the environment we wanted for our son. There was so much joy and happiness there—we just knew it was the right place for Creed.”

Better and Better

Kennedy Krieger’s special education schools serve students whose learning needs cannot be met by public schools. The Fairmount Campus serves students in prekindergarten through grade eight. The Institute’s Greenspring Campus in northwestern Baltimore is home to Kennedy Krieger High School, serving students in grade nine through age 21, and the LEAP* Program, for students ages 5 through 21 with complex academic, communication, social and behavioral needs. In Maryland’s Prince George’s County, the Institute’s Powder Mill Campus serves students in grade two through age 21.

When Creed was 6, he and his family moved from Hawaii to the mainland U.S. to give Creed greater access to medical and educational services. Creed attended public school through the second grade, then his teachers recommended nonpublic special education.

“Since Creed started at Kennedy Krieger, we’ve seen him change in so many ways,” Michelle says. “He’s gone from not really knowing how to interact with another student or verbalize when he needs help, to being able to play with other kids, and have a dialogue with us in his own fun, creative way. Every year, he just gets better and better.”

“Creed is really energetic, very positive and outgoing,” says behavioral specialist Robert Falloni, who’s worked with Creed for several years. Lunchtime can be hard for Creed, as he has some food aversions, so he often spends that time with Falloni—and a little karaoke machine. They sing—Creed loves Frank Sinatra songs—and enjoy lunch together. Falloni also works with Creed throughout the school day, helping Creed when he gets frustrated with his schoolwork. And Creed receives mental health services to further help him cope with his frustrations.

“Initially, Creed had trouble asking for help, and if he was stuck, he’d get upset,” says Falloni, who developed a checklist of things—deep breathing, sitting quietly—Creed could do to calm down. Falloni would talk Creed through his frustrations then transition him back to his schoolwork. “Now, if he needs help, he’ll say, ‘I need help.’ And if another student is having a tough time, he’ll tell the student, ‘It’s OK.’”

“When the tour ended, my husband and I looked at each other and said, ‘Wow, this is it!’ There were no other considerations. This was the environment we wanted for our son.”

— MICHELLE, CREED’S MOM

**Lifeskills and Education for Students with Autism and Other Pervasive Behavioral Challenges*

‘I Can Do It!’

Creed recently completed the sixth grade. During much of the past year, he attended school virtually, to adhere to pandemic-related social distancing protocols. “He rocked the virtual classroom,” Falloni says. “He knew the schedule, he knew the routine, and he’d be in the [virtual] waiting room when it was time for class.”

On his first day back in the classroom, “He came right in and was so happy and ready to be here,” says his teacher, Chelsey Bush. During one activity, “Someone else answered a question, and Creed turned around and said, ‘Well done!’”

Bush and assistant teacher Hannah Baron model positive thinking for their students. Baron sometimes pairs affirmation statements with yoga. “We’ll do the tree pose, and Creed will say his affirmation,” she explains. One day last spring, Baron was helping Creed with a math problem. “Before I could prompt him, he said, ‘I’m smart; I can do it!’” Baron says. “It was a breakthrough moment.”

“It’s really neat to watch Creed’s progress, from saying a couple of words and phrases here and there, to now having so much to say,” adds speech-language pathologist Christine Feinour, who’s worked with Creed for the past few years on speech, social skills, interacting with peers and problem-solving. “When I think of Creed, I think of this bright, creative student who brings so much joy to all of his teachers, peers and family.”

Creed’s parents are so glad they made that trip, four years ago, to visit Kennedy Krieger. “We want our son to be as independent as possible, and to be able to make friends and be confident and kind to others,” Michelle says. “I know that everyone at Kennedy Krieger is trying to help Creed learn, little by little, so he can grow and mature, and say, ‘I can do this, I understand that, I believe in myself.’ The more he can say that, the more he can be the best human he can be in this world.” — LT

Visit [KennedyKrieger.org/Fairmount](https://www.kennedykrieger.org/Fairmount) to learn more about the Institute’s Fairmount Campus.



Creed and speech-language pathologist Christine Feinour

An Amazing Recovery

Severely injured in a car accident right after finishing high school, Ally worked hard to recover from her injuries and get her life back.



ALLY ACCOMPLISHED AMAZING THINGS

in the three months after graduating from high school last year. They just weren't things she'd anticipated doing—or even needing to do at all.

On June 17, 2020, just days after finishing her senior year, Ally was injured in a car accident. The crash left her with two broken vertebrae, broken bones in her left ankle and knee, a collapsed lung and a severe brain injury. She'd been a passenger in the car.

Initially, Ally stayed at a hospital near her home in Virginia, in a coma and hooked up to a ventilator, a feeding tube and other medical apparatus. "I didn't know if she'd wake up, or always be in a wheelchair, or if she'd ever talk again," says her mother, Catherine.

Ally's brain was dangerously swollen. On June 20, while Ally's friends and family held a candlelight vigil outside her family's home, doctors removed a piece of Ally's skull to relieve the pressure in her brain. Buoyed by prayer and expert medical care, Ally stabilized. After back surgery a week later, she began opening her eyes—just fluttering her eyelids at first, and then starting to track her parents' movements in her hospital room. Soon it was time to talk about rehabilitation.

Daily Therapies and 24/7 Care

As Ally was 18 and no longer in high school, Ally's parents had to decide between an adult rehabilitation facility for Ally, or a pediatric one. Adult facilities help patients regain the skills and movements needed to get back to work, while pediatric ones focus on preparing patients to return to school. As Ally was college-bound, her parents chose Kennedy Krieger Institute's inpatient rehabilitation hospital, which admits patients from birth to 21 years old. "We figured it would be better for Ally to be with patients her age and younger, rather than her age and older," Catherine says. "I wanted her to be at a place that specializes in working with patients who are in school."

Ally arrived at Kennedy Krieger on July 15, 2020. "Every day was different," Ally recalls. She had at least an hour each of physical, occupational and speech therapies a day, and received psychology, neuropsychology, nutrition and social work services, as well as nursing care 24/7, including having a behavior rehabilitation assistant sit beside her at night. "We needed to be sure she wouldn't sleep on the side of her head where her piece of skull had been removed," explains inpatient clinical nurse Morgan Bowman.

"We ensured she had an active and structured therapy day, and that she received the nursing and medical support she needed," adds Dr. Beth S. Slomine, a neuropsychologist and co-director of the Institute's Center for Brain Injury Recovery. "We also met her where she was at—transitioning from high school to adulthood. It's a tough time for anyone, but even harder with a brain injury."

Ally's therapists carefully planned her therapies around the equipment she had to wear: a helmet to protect her brain, neck and torso braces to help her vertebrae heal, a boot to support broken bones in her left ankle and knee, and a tracheostomy tube in her neck so she could breathe.



“We were always having to adjust the braces, and it was hard for Ally, because initially, she couldn’t understand why she had to wear all of it,” says physical therapist Dr. Alissa Marzetti. “Once we could take those things off, she was more comfortable.”

Dr. Marzetti worked closely with occupational therapist Jessica Simermeyer to develop co-treatment sessions for Ally. “We’d base our sessions on what Ally was interested in and what would motivate her,” Dr. Marzetti explains.

“Those sessions were really successful, because we could engage Ally in more complex and rewarding activities,” Simermeyer adds. Ally went from relearning how to stand to standing while painting, shooting baskets and brushing her teeth. She also advanced from taking a few steps with a walker to walking on her own and using stairs. “Ally made so much progress, and was a really fun person to work with. She liked to joke a lot, and she truly has the power to light up a room.”

Ally’s speech returned, too. As she became more alert and responsive, she tried to say a few words, but the tracheostomy tube made speech difficult. “We worked on using a speaking valve that goes on top of the tracheostomy to produce voicing,” explains senior speech-language pathologist Kristy Chao. “Once she could tolerate the speaking valve, I helped her produce sounds with voicing.” Ally moved on to words, and then, after her brain had healed a little more, to full sentences and conversation.

“It was easy to celebrate Ally’s progress at Kennedy Krieger,” says John, Ally’s father. “She was always getting better, and we attribute that to the supportive environment at the Institute.”

‘Awesomeness’

By early August, Ally’s tracheostomy tube was out, and she was given the green light to eat again. Her parents brought in some of her favorites: Chick-fil-A chicken tenders, steak fries, fresh blueberries, blueberry Pop-Tarts and—best of all—Starbucks coffee drinks.

One of Ally’s favorite things to do at Kennedy Krieger was to visit the Institute’s therapy garden, and enjoy its flowers, trees and fountains.



One day, child life specialist Emily Winter-Cronan and therapeutic recreation specialist Kelly Schevitz created a spa day for Ally and Catherine in the garden, complete with eyelid-soothing cucumber slices, relaxing music and manicures. “Ally was working so hard,” Winter-Cronan says. “We wanted her to have a chance to relax and have fun.”



“Ally’s such a fun-loving, energetic person,” Dr. Marzetti says. “Whenever she was faced with a new challenge in her rehabilitation, her frequent response to the challenge—and reflection on her success—was ‘awesomeness.’ She always had a really great attitude, and was always motivated to get better—and get home.”

“It was easy to celebrate Ally’s progress at Kennedy Krieger. She was always getting better, and we attribute that to the supportive environment at the Institute.”

– John, Ally’s father

On September 16, 2020, Ally returned to the hospital where she’d had her craniotomy, to have the piece of her skull put back in place. Three days later, she was home. Her friends and family were waiting for her on her front lawn, cheering for her and all that she’d accomplished that summer.

Since then, Ally has continued to make incredible progress. “It’s amazing—I’ve been playing volleyball, taking community college classes, and in the fall, I’ll start at James Madison University,” Ally says.



“Right after the accident, I wondered what our future life would be like,” Catherine adds. “I didn’t think Ally would be able to get to where she is now. It’s miraculous.” –LT

Visit KennedyKrieger.org/Rehabilitation to learn more about rehabilitation programs at the Institute.

Ally (left of center) with her parents, John and Catherine, and siblings Jack, Katie and Patrick





‘A World of Difference’

After starting medication for epilepsy, Sam, who also has autism spectrum disorder, “became a part of the world,” his mother says.

Last summer, while on a family vacation, Sam lost consciousness for a few minutes.

His eyes rolled up, but he didn't shake. After he regained consciousness, he threw up.



His mother, Bethel, wasn't sure what had happened, and mentioned it the following week when Sam had his next appointment with Kennedy Krieger Institute's Center for Autism and Related Disorders (CARD). Sam, who's 10 and has autism spectrum disorder (ASD), has been a patient at CARD for the past four years.

"I thought maybe it was something he ate, because he threw up," Bethel says. But pediatric nurse practitioner Sheila Umayam, who'd just taken over Sam's care after his previous clinician had retired, suspected something else—an absence seizure, formerly known as a petit mal seizure.

"The appointment was originally scheduled to be a routine developmental follow-up and to discuss Sam's attention and learning difficulties in school," Umayam says. "But sometimes, absence seizures can appear like inattention, and can contribute to learning difficulties." Sam's loss of consciousness could have been a seizure—and so, too, could have been the times he appeared to be inattentive in school.



During the second half of the appointment, which took place via telehealth due to COVID-19 precautions, Umayam, Sam and Bethel were joined by Dr. Deepa Menon, CARD's assistant medical director, who agreed that Sam's loss of consciousness and attention difficulties might be due to seizures. They agreed on an immediate course of action: an electroencephalogram, or EEG—a test to study the electrical activity in Sam's brain, followed by baseline blood work, an MRI and follow-up care with Kennedy Krieger's neurology team, in coordination with Sam's CARD clinicians.

A New Diagnosis

As it turned out, Sam did have epilepsy, as revealed by the EEG. Epilepsy is not an uncommon diagnosis for children with ASD—between 8% and 30% of children with ASD also have epilepsy, Dr. Menon says. Seizures typically peak before age 5 or in adolescence or early adulthood, and often happen before, during or after sleeping.

"Detecting epilepsy in children with ASD can be complicated by any communication or behavioral challenges they may have," Dr. Menon says. "At CARD, if there's ever any concern about seizures, we refer the child for an overnight EEG. And then if we do detect seizures, we can prescribe medication to reduce or eliminate the seizures."

The next week, Sam was at Kennedy Krieger's Clinical Neurophysiology Clinic and Laboratory for an overnight EEG. "We're very lucky to have neurologists and EEG technicians skilled in working with children with ASD and other neurodevelopmental disorders, who don't always understand why they're getting an EEG," which involves having dozens of small electrodes lightly glued to the head for several hours, Dr. Menon explains.



Not long after those electrodes were off Sam's head, Dr. Menon and her colleagues received the EEG results, which indicated Sam was experiencing both absence and focal (formerly known as grand mal) seizures. "We started him right away on medication"—liquid Depakote, Dr. Menon says.

'Imagine the Impossible'

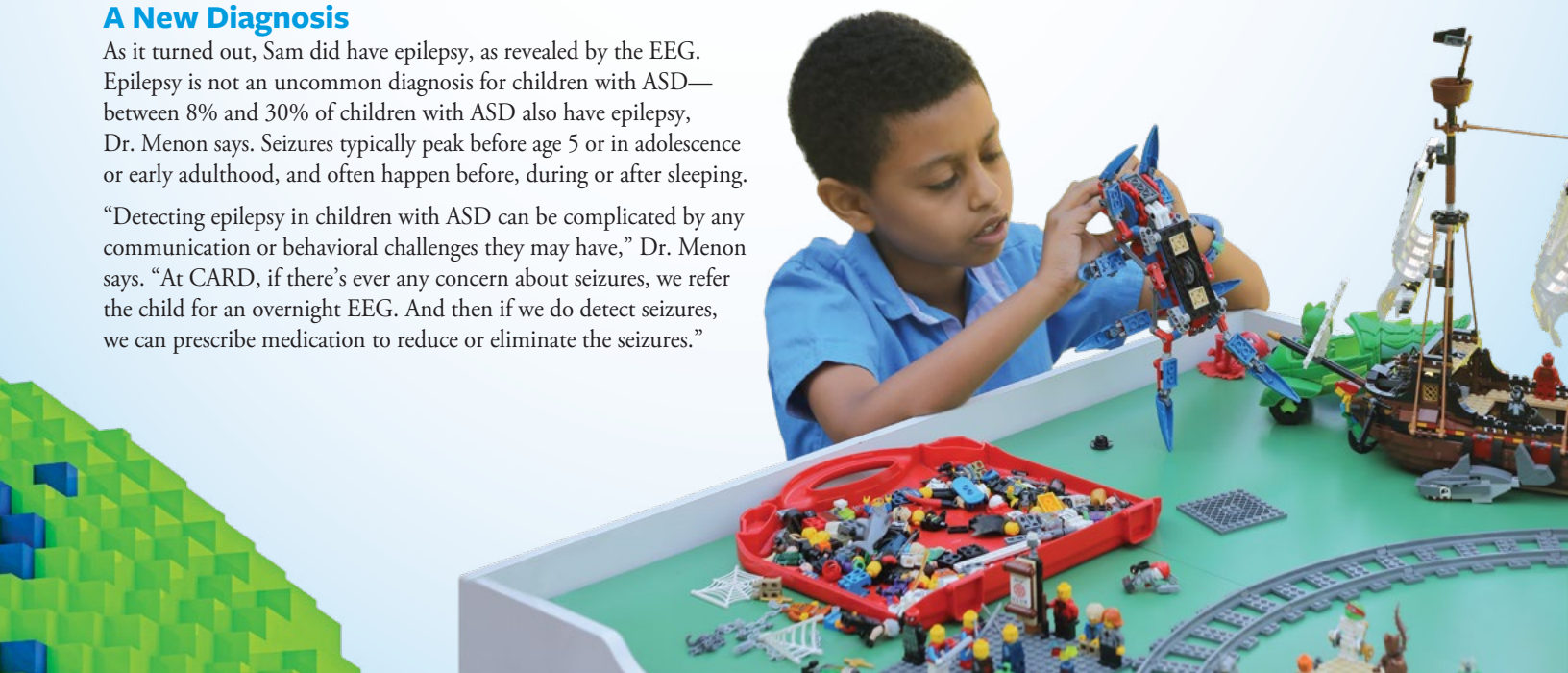
"After Sam started taking seizure medication, it's like the world opened up for him," Bethel says. "He was finally able to understand us and express himself. There are times when he's a chatterbox. It's like saying, 'Imagine the impossible for Sam,'" and then watching it happen.

"His vocabulary has exploded. He's happy, and he's now a very social child—he loves being with other kids," Bethel adds. "He just didn't have the language and awareness to be with other people," before starting on the medication. "Now, if he's with other kids, he's always attentive; he's always there. His mindset is in the game, and he just became a part of the world."

Sam's older sister plays the piano—and all of a sudden, Sam started playing the piano, too. Bethel gave him a few lessons, and soon he was reading music and playing simple songs. And he loves Lego bricks. "He doesn't even look at the manual. He just gets a new box of Legos and assembles the models himself," Bethel says.

The piano lessons didn't last long, though. "Now he's a rebellious 10-year-old wanting to do his own thing," Bethel says with a smile. But that's a good thing. "We like those 'push-the-button' behaviors, because that's typical growth."

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“His vocabulary has exploded. He’s happy, and he’s now a very social child—he loves being with other kids.”

– Bethel, Sam’s mom

A Medication Tweak

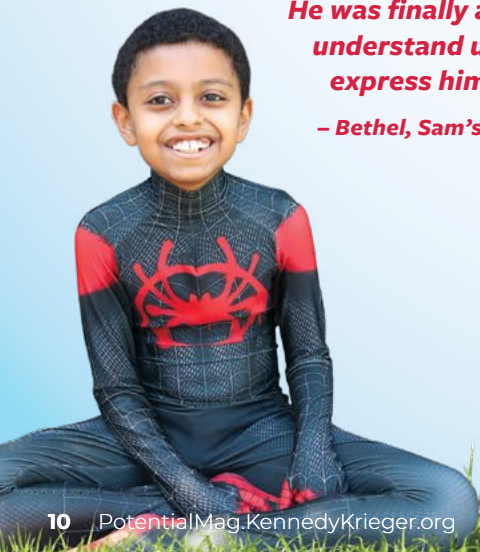
Earlier this year, Sam had a follow-up EEG—only four hours long this time—to monitor his progress. He was still having occasional staring spells, and Dr. Joseph Scafidi, a pediatric neurologist who had just started working at Kennedy Krieger, wanted to know why. The shorter EEG allowed Dr. Scafidi to get an update on Sam’s brain activity without putting Sam through an overnight study again.

This second EEG confirmed that Sam was still having some small seizures. Because liquid Depakote is absorbed quickly by the body, leaving downtime between doses when the medication isn’t having as much of an effect, Dr. Scafidi wanted to see if Sam could tolerate Depakote capsules. The “sprinkles” contained in each capsule could even out the medication’s effect across the day.

Dr. Scafidi worked with Bethel to come up with a way for Sam to take the capsules. Swallowing them was difficult for Sam, but opening up each capsule and sprinkling its contents onto a spoonful of Jell-O or pudding worked. Since starting on the capsules, Sam’s been seizure-free.

“After Sam started taking seizure medication, it’s like the world opened up for him. He was finally able to understand us and express himself.”

– Bethel, Sam’s mom



Sam has frequent check-ins with Dr. Scafidi to adjust his medication dosage as his height and weight increase. After two years without seizures, Sam may be able to discontinue the Depakote, but either way, he’ll remain monitored by Dr. Scafidi and his other Kennedy Krieger clinicians.

“I try my best to build close relationships with my patients and their families, so they know they can always contact me with any concerns,” he says.

Sam’s parents are amazed by their son’s progress. “Sam has been a surprise, all around,” Bethel says.

“If not for Ms. Umayam’s detailed history-checking and keen investigating skills, Sam’s seizures might not have been discovered,” she adds. “Last year, if someone had told us that we would get to this level and Sam would be a part of the community as he is now, I would never have believed that. Since beginning his anti-seizure medication, we have seen a world of difference in Sam’s life.” – *LT*

Visit [KennedyKrieger.org/Sam](https://www.KennedyKrieger.org/Sam) to watch a video about Sam.

Visit [KennedyKrieger.org/CARD](https://www.KennedyKrieger.org/CARD) to learn more about the Institute’s Center for Autism and Related Disorders, and visit [KennedyKrieger.org/Neurophysiology](https://www.KennedyKrieger.org/Neurophysiology) to learn more about the Institute’s Clinical Neurophysiology Clinic and Laboratory.

Keeping Schools OPEN

THE INSTITUTE IS TAKING PART IN A STUDY THAT EXAMINES HOW WELL FREQUENT CORONAVIRUS TESTING WORKS AT PREVENTING COVID-19 OUTBREAKS AND ALLOWING IN-PERSON LEARNING TO CONTINUE.

Last spring, as communities implemented restrictions to limit the spread of the coronavirus, schools across the country shifted from in-person to virtual learning. It was a stressful change for many students, particularly those with intellectual and developmental disabilities, many of whom require hands-on instruction, speech and occupational therapies, and other specialized services throughout the school day.

For them, a full return to the physical classroom—five days a week—is crucial. But with the pandemic lingering and younger children not yet eligible to receive a COVID-19 vaccine, additional steps to ensure infection control are needed.

That's where testing comes in. Kennedy Krieger Institute is taking part in a study that examines how well frequent coronavirus testing of students and school staff members works at allowing as many students with disabilities as possible to attend school in person, five days a week. The study is part of a larger project funded by the National Institutes of Health and overseen by the Washington University School of Medicine in St. Louis. Advising Kennedy Krieger on its role in the study is the community advisory board of the Maryland Center for Developmental Disabilities, the Institute's advocacy arm.

In July, Kennedy Krieger began administering weekly asymptomatic coronavirus tests to all students whose parents or guardians had agreed to allow them to participate in the study. School staff members may choose to be tested, too. The tests are rapid and noninvasive, with no swabs needed—participants just need to drool saliva into a cup.

"We're excited to add weekly testing to our COVID-19 safety toolkit so students with disabilities are able to more safely and fully return to in-person instruction," says Dr. Linda Myers, the Institute's vice president of school programs and one of the study's co-principal investigators. "We are hopeful that the results of this study will be helpful for school communities across the country, as we continue to navigate the pandemic."



"Routine testing is important, since many children with intellectual and developmental disabilities have difficulty with preventive measures, such as mask-wearing, hand hygiene, and social distancing," explains Dr. Luther Kalb, director of the Informatics Program at the Institute's Center for Autism and Related Disorders, and another co-principal investigator of the study. "This puts them at increased risk for contracting the coronavirus. Many of these children also have underlying medical conditions that put them at a higher risk for having poor outcomes if they develop COVID-19."

To understand the best ways to prepare a child with intellectual or developmental disabilities for weekly testing, Kennedy Krieger conducted focus groups with parents of students attending Kennedy Krieger schools. Among other things, the focus groups revealed that preparing a child to receive a coronavirus test in the very environment in which the test will take place is extremely helpful.

Kennedy Krieger School Programs' four schools, which serve approximately 500 students a year, will continue the tests through June 2022. "Ongoing testing will be particularly important as we head into the school year, the holidays, and the cold and flu season," Dr. Myers says.

"We'll be one of the very few schools serving children with disabilities and doing routine testing throughout the winter," Dr. Kalb adds. "What we find as we do the study will have national implications, but it'll also give peace of mind to families and staff members, since we'll be reporting coronavirus positivity rates routinely. I think everyone will feel more comfortable knowing we are monitoring COVID-19 as we move through the year." – LT

"What we find as we do the study will have national implications."

– DR. LUTHER KALB

Visit KennedyKrieger.org/COVIDTestStudy to learn more about the study. Email the study team at COVIDStudy@KennedyKrieger.org if you are a Kennedy Krieger School Programs staff member or a parent or guardian of a child attending a Kennedy Krieger school and would like to sign up to participate in this study.



Helping Babies

Flourish

When Lisa gave birth to her son 16 weeks early, she and her husband, Glen, were caught completely off guard. Not only had they become parents months ahead of schedule, but Baby Alexander was only 1.49 pounds—and his brain was bleeding.

“Initially, we didn’t know if it was a Grade 3 or Grade 4 brain bleed,” Lisa recalls. “After a couple of days, doctors settled on Grade 3.” That meant Alexander needed to be monitored very closely, his head circumference measured several times a day to track the bleeding.

Alexander, now 3, was in neonatal intensive care for 108 days, the last month and a half of that time at The Johns Hopkins Hospital. There, Dr. Joanna Burton, a developmental neurologist and co-director of Kennedy Krieger Institute’s Infant Neurodevelopment Center, visited him frequently. “We’d talk and she’d evaluate Alexander,” Lisa says, to ensure that any therapies and interventions Alexander needed could begin as early as possible.

“There was such a sense of relief when Dr. Burton and the Kennedy Krieger neurodevelopment team did their weekly check-in,” Lisa adds. “Considering Alexander’s brain bleeds and prematurity, there were so many things doctors had prepared us for,” including cerebral palsy and autism spectrum disorder. “It was all on the table, which was frightening. But during one of the many visits from Alexander’s medical care team, a neurosurgeon on rounds stopped me from worrying when she said, ‘It’s all environmental.’ I just needed to provide the right environment to support Alexander’s growth.”

EARLY DETECTION AND INTERVENTION

After Alexander was discharged from the hospital, he began regular appointments at the Infant Neurodevelopment Center, an interdisciplinary program that evaluates and treats infants and very young children with a wide variety of medical conditions, including premature birth and perinatal brain injury, that could put them at risk for developmental delays. The center was founded by neonatologist and neurodevelopmental disability specialist Dr. Marilee Allen, who recently retired from Kennedy Krieger.

“The center’s goal is for each of its patients to grow into their best self,” Dr. Burton says. To accomplish that, the center assesses each baby’s current functioning, identifies their risk for future challenges, provides early identification and intervention services when necessary, and supports the baby’s parents or guardians during their child’s earliest years.

The center provides inpatient consultations for families like Alexander’s at both The Johns Hopkins Hospital and Johns Hopkins Bayview Medical Center, and evaluates patients at Kennedy Krieger within a few months of discharge from the NICU. A truly interdisciplinary team, the center’s staff of 18 includes neurologists, neonatologists, developmental pediatricians, neuropsychologists, nutritionists, nurses, social workers, and occupational and physical therapists. Patients are matched with clinicians to target each patient’s developmental skills and age.

The Infant Neurodevelopment Center’s focus on early detection, diagnosis and treatment ensures its young patients get the best possible start in life—and that their families get the support they need, too.



“With Kennedy Krieger, we always know we’re not alone.”

– Lisa, mother of Alexander

Patients typically have appointments at the center three or four times in their first year of life and twice in their second year, with additional appointments and evaluations as necessary. The center fully evaluates each patient before they transition to receiving care from pediatric specialists outside the center who work with older children. The results of the evaluation help guide that shift in medical care, as well as the child's transition to preschool.

One of the things that makes the center unique is that neuropsychologists are highly involved in patient evaluations. "The traditional model for NICU follow-up clinics is a blend of medical care and physical therapy," Dr. Burton says. "But we also look at cognition and the interplay of all domains of development to ensure accurate diagnoses, the right early interventions, and the best possible future for each of our young patients."

"Often, it's believed that neuropsychologists only see children around school age and beyond, but there are neuropsychologists who specialize in working with infants and toddlers," explains Dr. Gwendolyn Gerner, a developmental neuropsychologist and co-director of the center.

"Through a combination of standardized tests, consideration of a child's medical history, and behavioral observations, we're able to provide important recommendations to support development and learning, even in the face of more challenging motor and sensory impairments," she says. "When we provide individualized interdisciplinary evaluations that lead to specific, tailored recommendations across different time points in development, the results are powerful. It's amazing to watch our young patients blossom in their own unique ways."

The center is part of the Cerebral Palsy Foundation Early Diagnosis and Intervention network, which is working to lower the age of diagnosis for cerebral palsy (CP), and to develop early interventions for babies and young children diagnosed with CP. Across the country, the average age of diagnosis for CP is between 2 and 3 years old, but the center is now diagnosing babies with CP at an average age of 11 months past their full-term due date, Dr. Burton explains.

"The importance of that is two-fold," she says. "There's growing evidence that parents are suspecting their child has CP before their child is diagnosed, and a long diagnostic period causes anxiety for parents. But the critical piece is that early CP-specific therapy improves outcomes and functional levels. Getting kids the therapeutic interventions they need as early as possible truly changes their lives."

LESSONS FROM TELEHEALTH

In March of 2020, the COVID-19 pandemic led many of Kennedy Krieger's outpatient clinics to offer services via telehealth. The center quickly developed a virtual evaluation model to allow different members of its team to "visit" with a patient and the patient's parents or guardians, confer with each other, and then talk with the parents or guardians about the evaluation's results—all during a single telehealth appointment.

Initially, Dr. Burton, Dr. Gerner and their colleagues didn't think they'd be able to make diagnoses during telehealth appointments. "But on the first day of telehealth, we broke that rule, with three diagnoses," Dr. Burton says.

While telehealth appointments aren't ideal for every patient and family, they are helpful for many. "If a baby is on oxygen, or if a family has infant triplets who all need to be evaluated, or if it's winter and there's bad weather, telehealth can be a great option to ensure that those crucial early evaluations aren't postponed," Dr. Gerner says.

THE RIGHT ENVIRONMENT

Alexander, who's had both in-person and telehealth appointments through the center, has made incredible progress. "We're giving him the ability to be in an environment that supports his learning," Lisa says, and Alexander is walking and talking up a storm—in English and Spanish. He's gone from visiting the Infant Neurodevelopment Center every few months, to returning for an evaluation about once a year.

"Now, when people meet Alexander, I say, 'He's about to turn 3,' not 'He's a 24-weeker,'" Glen says. "My son is thriving so well that I want to introduce him as a 3-year-old who's just had his first soccer practice."

"Kennedy Krieger helped us find ways to allow Alexander to learn in the way that he needs to learn," Lisa adds. "Having Kennedy Krieger to lean back on, and to hear them say, 'Hey Mom, hey Dad, you're doing a great job, and everything's going to be OK'—that, for us, is just paramount. The journey of being a parent of a micropremie is difficult, but with Kennedy Krieger, we always know we're not alone." —LT

Visit [KennedyKrieger.org/INC](https://www.KennedyKrieger.org/INC) to learn more and watch videos about the Institute's Infant Neurodevelopment Center.



'A Voice in This BIG WORLD'

Caring for her baby with CP, along with overcoming personal obstacles, was overwhelming. But Jeanette found her way—and helped her son, Mo, find his, too.

By Jeanette Patterson, mother of Morris "Mo" Worrell, as told to Christianna McCausland



Seven months into my pregnancy, I started having contractions and went to the hospital. They discovered one of my twin babies was stillborn. My system was septic, and Mo wasn't getting what he needed. When I delivered Morris, they told me it was likely he'd have cerebral palsy [CP].

Mo only weighed one pound at birth and spent 45 days in the NICU at The Johns Hopkins Hospital. Then they referred us to Kennedy Krieger Institute, which has been with us ever since, every step of the way.

Mo had a lot of growth and development issues. When he was a year old, Kennedy Krieger evaluated him and diagnosed him with spastic quadriplegia CP. He went through countless sessions of occupational and physical therapy, evaluations of his speech, and evaluations for accessible technology for his wheelchair. He only had one surgery, a hamstring surgery. Last year, he got a new wheelchair with headlights and a phone charger!

When Mo was little, I worried about putting AFOs [orthotic braces] on him, because I didn't want it to look like something was wrong. But Dr. [Alexander H.] Hoon [Jr., director of the Institute's Phelps Center for Cerebral Palsy and Neurodevelopmental Medicine], who's been with us since Day 1 and made us a part of his life, assured me that it wasn't about how Mo looked. It was about what Mo needed so he

could develop and be a part of society. After that talk, I realized I needed Mo to wear shoes so he wouldn't have club feet. He needed the AFOs' support so there wouldn't be problems later on.

It was all so overwhelming that I didn't know, at 23 years old, how to cope. I was feeding Mo with a tube I had to put through his nose into his stomach. I started to self-medicate with drugs and alcohol. Mo's dad went to prison, then came home and was doing well. Then he was murdered on his mother's porch. My daughter, who's seven years older than Mo, was forced to grow up quickly. She had to survive to be the secondary parent to herself and Mo, and we were on our own. Today, my daughter is a mother of two, and her son was the valedictorian of his high school class of 2021.

I went to Dr. Hoon and let him know I was struggling, and he and the social workers supported me. I didn't have anyone else who could talk to me about what I was going through. Kennedy Krieger pretty much told me that I had to change or I'd die, and then what would happen to Mo? They introduced me to Alcoholics Anonymous. AA renewed my strength with a loving and caring power greater than myself. Our life journey transformed continuously into spiritual awakenings. Kennedy Krieger helped me write letters to get adequate housing. I went from no housing to low-income housing to being a homeowner for the last 11 years. I've been employed for 13 years by the state of Maryland. I'm now in my 21st year of sobriety!

Mo has gone from learning how to speak to now being an artist. I set up an easel in front of him and give him a paintbrush in his left hand, and he paints. This really came out when we moved to our house, because everything here is more accessible for him. Art gives him a voice and self-expression. He wants to start his own company, to get together peers of different talents on one platform. Kennedy Krieger gave him that inspiration. They let him know he has a voice in this big world.

"I like surprising people with my talent. It started out as a hobby. I want to start my own art company."

— Morris "Mo" Worrell

Mo, 34, is a patient of Kennedy Krieger Institute's Phelps Center for Cerebral Palsy and Neurodevelopmental Medicine, and receives care from many people and programs throughout the Institute. Visit [KennedyKrieger.org/PhelpsCenter](https://www.kennedykrieger.org/PhelpsCenter) to learn more about the center and the services it offers.



SAVE THE DATES

Kennedy Krieger's events are a great way to bring family and community members together!

Visit KennedyKrieger.org/Events to explore all of the exciting things that are happening, and to support our work.

Please note: Current infection control protocols will be followed for all Institute events, and if necessary, event format changes will be made.



This year's Hats & Horses Benefiting Kennedy Krieger Institute is scheduled for Thursday, September 30, at our exciting new venue—The Winslow at the Parker Metal Building in downtown Baltimore. This in-person event will feature inspiring stories, entertainment, gourmet catering by Linwoods and a silent auction of special items.

Hats & Horses is an annual event organized and hosted by the Women's Initiative Network (WIN) for Kennedy Krieger Institute, a volunteer organization dedicated to raising funds for and awareness of the Institute. Visit KennedyKrieger.org/Derby for more information.



Santa Needs Helpers! November 26–28, 2021 • Maryland State Fairgrounds

Planning for the Institute's 32nd annual Festival of Trees is underway! Held the weekend after Thanksgiving, it's the largest holiday-themed festival of its kind on the East Coast, and the unofficial kickoff to the holiday season. We're looking for individuals and organizations interested in:

- Sponsoring
- Volunteering
- Donating auction items
- Designing a tree, wreath or gingerbread house
- Providing shopping opportunities as a vendor

Send an email to FestivalOfTrees@KennedyKrieger.org or visit FestivalOfTrees.KennedyKrieger.org to learn more.

Join us on social media! Visit: KennedyKrieger.org/Connect



Patients and Students at Kennedy Krieger Need Your Help!

Do you want to make a difference for children and families? Help our patients and students by becoming a monthly donor. Visit KennedyKrieger.org/Monthly to learn more and sign up.

Another way to make a lasting impact is to include Kennedy Krieger in your estate and charitable gift plans. Leave a legacy to reflect the values you want to express and pass down to future generations. Visit KennedyKrieger.org/PlannedGiving to learn more.

One of the easiest ways to help Kennedy Krieger is to give through a donor-advised fund. Donate the amount you want, when you want to give it, in a way that is tax-advantageous to you. Visit KennedyKrieger.org/DonorAdvised to learn more.



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When you give to Kennedy Krieger Institute, you're helping us see beyond limits for patients like Sam. Your gift supports groundbreaking research and care that bring hope and transform lives. Thank you so much!

Make your donation today using the return envelope in this issue, or online at: **KennedyKrieger.org/PS21**

The individualized care that Sam, 10, pictured at left with his sister and mother, receives at Kennedy Krieger allows him to learn, play, grow and thrive. Read Sam's story on page 8.

Giving to Kennedy Krieger

WHY I GIVE

"My favorite way to give to Kennedy Krieger is to volunteer in the playroom for the Institute's Child Life and Therapeutic Recreation Department," says Cynthia Cavanaugh, co-president of the Women's Initiative Network (WIN) for Kennedy Krieger Institute, a volunteer organization dedicated to raising funds for and awareness of the Institute.

"Kids visit the room between therapies, and volunteers play games and paint pictures with the kids. Volunteers get a window into the magic that happens at Kennedy Krieger, as they watch kids make progress and have fun," adds Cavanaugh, who generously donates both time and resources to the Institute.

"I truly feel like I get more out of it than the kids do. The children are amazing, and staff members fill the room with energy and love. It's such an incredible, joyful experience to volunteer at Kennedy Krieger."

Visit KennedyKrieger.org/WIN for more information about WIN, and visit KennedyKrieger.org/WINCynthia to learn more about Cynthia's volunteer work with Kennedy Krieger.

Cynthia Cavanaugh visits with a patient at Kennedy Krieger.

