

potential

A publication of Kennedy Krieger Institute Summer 2022

Astronomical Gains

Helping Daniel be the kid he was meant to be

Care and Reassurance

Support for Cora—and for her family, too

Resilience and Giving Back

For Ethan, rehab is about more than just himself

A Calling and a Promise

NICU alum Ariel heads to med school to help others



Kennedy Krieger Institute





Greetings From Our President

Friends,

There's an amazing feeling I get when I see a child who could not previously walk, talk or sit up accomplish these feats. It takes hard work on the part of the child, their parents and our specialists to reach those milestones, but every single second of effort is worth it to see the smile on their face and tears of joy in their parents' eyes.

Just look at Daniel on the cover of this issue! He runs around and knows three languages—you'd never guess he once struggled to walk and talk. Kids like Daniel are the reason Kennedy Krieger Institute exists. He's been receiving therapy at the Institute since he was a baby. As you read the story about him and his journey, you'll learn about the multiple disorders he was born with that combine to make a very complex list of challenges. But complex is our specialty!

There are many exciting stories like Daniel's happening every day at Kennedy Krieger. Please read on to learn about Ariel, who was a patient at the Institute as an infant and is now in medical school, and Alexis, who with the help of our experts in pediatric pain, is now living independently and running an aspiring nonprofit organization of her own.

Please check out the last page of this issue to learn about our upcoming events. They're fun, and you'll get to meet people who've received care at, or who support, Kennedy Krieger. The funds they raise fuel our ongoing work. Festival of Trees will be back at the Maryland State Fairgrounds this year, with special infection control measures in place and lots of excitement for all ages. We hope to see you there!

Whether you're a community member, legislator, former or current patient or student, family member of a patient or student, board or staff member, or cherished donor, you matter greatly to us, and your feedback matters, too. We'd love to hear your comments about our magazine. Just visit [KennedyKrieger.org/Potential](https://www.kennedykrieger.org/Potential) or scan the QR code below to share your thoughts with us.

Thank you for all you do to help make stories like these happen!

Warm regards,

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



On the cover: Daniel is a patient of Kennedy Krieger Institute. Turn to Page 8 to read more about Daniel.

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for more remarkable stories, news and updates.

Drawing Strength FROM Serving Others

At 23, Alexis Byers is already making a difference in the world. She's the founder and director of Knock Back, Let Fly, an aspiring nonprofit organization that prepares activity boxes for kids experiencing hospitalization. She also works for National Trafficking Sheltered Alliance, a nonprofit anti-trafficking organization, and is getting her master's degree in homeland security and emergency preparedness.

But if you'd told her a year ago that she'd be doing all this today, "I never would have believed you," she says.

When Alexis was 17, she developed complex regional pain syndrome (CRPS). For five years, she experienced constant, excruciating pain on a daily basis. Her arms and hands were particularly affected. She couldn't even write her name.

Alexis learned about Kennedy Krieger Institute's services for chronic pain from a fellow member of a CRPS support group. In January of 2021, she started a two-month course of treatment at the Institute's Specialized Transition Program (STP), a neurorehabilitation day hospital, where she learned ways to reduce and manage the pain. Daily physical and occupational therapies soon had her using her arms and hands again.

It wasn't easy. "I had to develop a specific mindset," she explains. "I had to work with the pain, instead of against it. But my care team believed in me on a level that I have never seen before. They taught me that it doesn't matter how many things need to be done in a day—you can do them all, as long as you give yourself some time, and some grace."

Alexis continues to use that approach, not just for her ongoing physical and occupational therapies to help keep her pain at a manageable level, but also in balancing the many demands of a job, graduate school and managing her organization.

She started Knock Back, Let Fly when she was 17 and going from one doctor to another in search of an effective treatment for CRPS. "I was in and out of hospitals frequently, but would see young kids staying in the hospital who didn't get to go home. I wanted to do something to say to them, 'I see you, and I notice what you're going through.'"

Alexis started raising funds to buy things like coloring books, crayons, games and small toys for the kids, then brought community members together to assemble the items into boxes, which she then delivered to pediatric hospitals. Doing something for others, she found, gave her life purpose, and motivated her to hold out hope that she'd one day get better. After her treatment at STP, and again in August of 2022, she donated dozens of boxes to the program, as well as to Kennedy Krieger's inpatient hospital.

Alexis still has occasional appointments at Kennedy Krieger. "They never make me feel badly about my condition, or that I'm supposed to have dealt with it already," she says. "It just feels really good to have people constantly rooting for you. It's hard to put into words how much Kennedy Krieger helped me. They changed my life."

And now, Alexis is helping others, through her work, studies and organization, and her outreach to others with CRPS. "I've talked with people across the nation with CRPS or a pain condition of some sort. Having this condition isn't easy, but having someone there who knows what you're going through helps."

With Alexis' pain now at a manageable level, she's dreaming bigger than she's dared to dream in a long time. She just moved into her first apartment—in Baltimore, a city she associates with healing and getting back her independence. She's looking forward to traveling and doing activities she hasn't done in years. And yet, her primary focus remains on others. "I just want to continue helping people." —LT

Visit KennedyKrieger.org/Alexis for a video interview with Alexis, visit KennedyKrieger.org/Pain to learn more about the Institute's Pediatric Pain Rehabilitation Program, and visit knockbackletfly.com to learn more about Alexis' organization.



"I just want to continue helping people."

—ALEXIS BYERS

Care for Cora— and Reassurance for Her Family

Clinicians from across Kennedy Krieger collaborate to help Cora learn, grow and thrive, and to support her family, too.

Cora, 8, loves being silly and playing with her older sister. “She’s a bundle of energy,” her mom, Liz, says. “She’s always very excited, and has a great sense of humor. She loves meeting new people and learning all about them.”

Over the past couple of years, Cora has gotten to know quite a few new people, including the members of her interdisciplinary care team at Kennedy Krieger Institute. They work together to ensure that every time Cora and her family visit the Institute, they learn more about Cora and how to support her as she learns, grows and thrives.

On February 26, 2021, Cora was diagnosed with fragile X syndrome. With Rare Disease Day just two days later, her family dubbed February 26 “Cora’s Day.” It’s a big day for them, as it’s when they learned, after nearly seven years of searching for answers, the cause of Cora’s delayed milestones.

“Finally, we knew for sure what was going on,” Liz says. “It was a relief—but also a feeling of being overwhelmed. I felt like I needed to make up for the previous six years, when I didn’t have that information.”

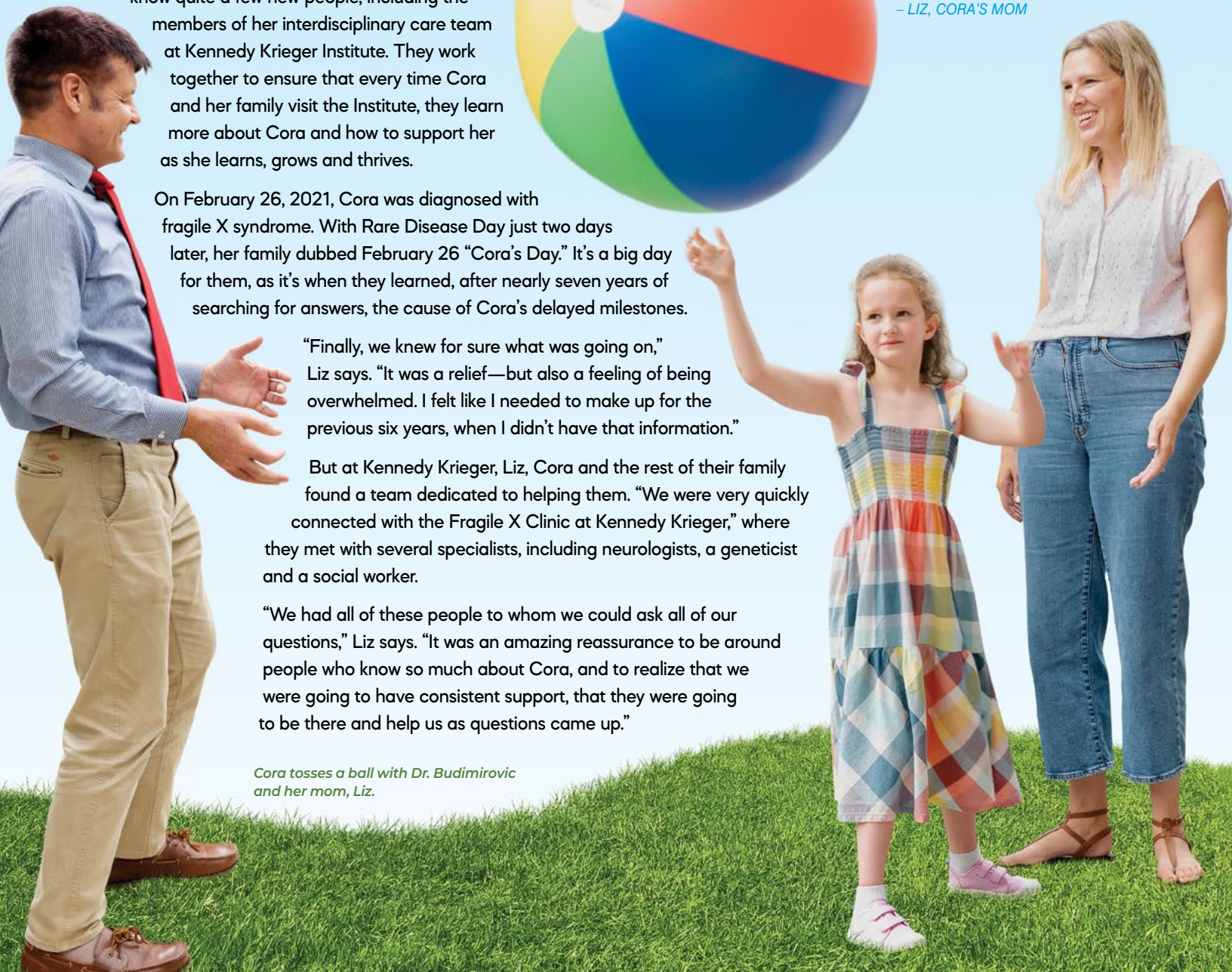
But at Kennedy Krieger, Liz, Cora and the rest of their family found a team dedicated to helping them. “We were very quickly connected with the Fragile X Clinic at Kennedy Krieger,” where they met with several specialists, including neurologists, a geneticist and a social worker.

“We had all of these people to whom we could ask all of our questions,” Liz says. “It was an amazing reassurance to be around people who know so much about Cora, and to realize that we were going to have consistent support, that they were going to be there and help us as questions came up.”

Cora tosses a ball with Dr. Budimirovic and her mom, Liz.

“It’s been life-changing having Kennedy Krieger on our team... and the reassurance that we’re doing all the things we should be doing to help Cora.”

—LIZ, CORA’S MOM



A Rare Diagnosis

Cora came to Kennedy Krieger in 2020 for an evaluation for a neuromuscular disorder that runs in the family. Her parents wondered if she had the disorder or a variant of it, and if so, if it was causing her developmental delays. “We asked around, and looked online, searching for answers,” Liz says. “Everyone was recommending we go to Kennedy Krieger,” so Liz gave the Institute a call.

Cora and her family met with Dr. Matthew Elrick, a pediatric neurologist at the Institute’s Center for Genetic Muscle Disorders and Brachial Plexus Injury Clinic. “We looked at Cora’s family as a unit, rather than just at Cora alone, to determine which gene was responsible for the neuromuscular disorder in several family members, if that gene could also cause Cora’s global developmental delay, and if not, what else might explain Cora’s symptoms,” he says.

What they found was that Cora did have the neuromuscular condition that runs in her family, but it was mild and not the cause of her global developmental delay. A more in-depth look at her symptoms suggested she might have fragile X syndrome, which can be associated with autism spectrum disorder (ASD) and other neurobehavioral difficulties. Genetic *FMR1* (fragile X) gene testing confirmed the fragile X syndrome diagnosis.

Testing also found that the cause of Cora’s diagnosis wasn’t a mutation of the gene associated with fragile X syndrome, as is the case for about 99% of people with the condition, but a deletion of that gene altogether in one of Cora’s X chromosomes, explains pediatric neuropsychiatrist Dr. Dejan Budimirovic, a co-director of the Institute’s Fragile X Clinic and an expert in fragile X syndrome. But Cora’s other X chromosome does not have the deletion—or even a mutation—of the gene. That’s why she’s not quite as affected by fragile X syndrome as others with the syndrome are—and why it was so hard to diagnose her.

“Cora does have motor and language delays, but she is, thanks to the great effort of her family and school, able to attend her local school,” with an individualized education program (IEP) in place, and one-on-one learning with a teacher or paraprofessional educator during much of the day, Dr. Budimirovic says.



With these accommodations, Cora is able to spend much of the school day in an integrated classroom with other kids, which gives her the social interactions she needs and loves.

A Strengths-Based Approach

Cora also has a mild form of ASD. “It’s common for kids—especially boys—with fragile X syndrome to have autism,” explains Dr. Allison Mostow, a clinical psychologist at the Institute’s Center for Autism and Related Disorders. Things like making eye contact and imitating gestures can be difficult for Cora, and she’s sensitive to noise and touch.

“But we were really struck by how social Cora is,” Dr. Mostow says. “She really wants to have those social interactions with other people.”

Cora sees Dr. Mostow and Dr. Budimirovic regularly. “We’re helping her learn strategies to focus her attention on learning when she’s at school,” Dr. Mostow says, so she can keep learning in an integrated classroom with her peers. “We focus on her strengths. Every kid has great potential, and seeing kids as individuals is something we really focus on.”

That approach has benefited Cora—and her family—enormously, allowing Cora to enjoy all that childhood has to offer, and her family the peace of mind that comes with knowing their child is receiving the best care possible.

“It’s been life-changing,” Liz says, “having Kennedy Krieger on our team and people we can bounce ideas off of, treatments we can try, and the reassurance that we’re doing all the things we should be doing to help Cora.” – LT

Visit [KennedyKrieger.org/FragileXClinic](https://www.kennedykrieger.org/FragileXClinic) to learn more about the Institute’s Fragile X Clinic.

Above, center: Cora has a music therapy session with music therapist Jordan Marshall (not affiliated with Kennedy Krieger).



Resilience and Giving Back

During rehabilitation at Kennedy Krieger's inpatient hospital following a brain injury, Ethan decided to make his recovery about more than just himself.

A few weeks into his stay at Kennedy Krieger Institute's inpatient rehabilitation hospital, Ethan pondered his future.

It was the summer of 2020, he was slated to start his senior year of high school soon, and in about six months, he'd turn 18. If he wanted to become an Eagle Scout—a longtime dream of his—he'd need to complete an Eagle Scout project before his 18th birthday.

"I'm so grateful for all that Kennedy Krieger did to help me. It felt really good to be able to give back." – Ethan

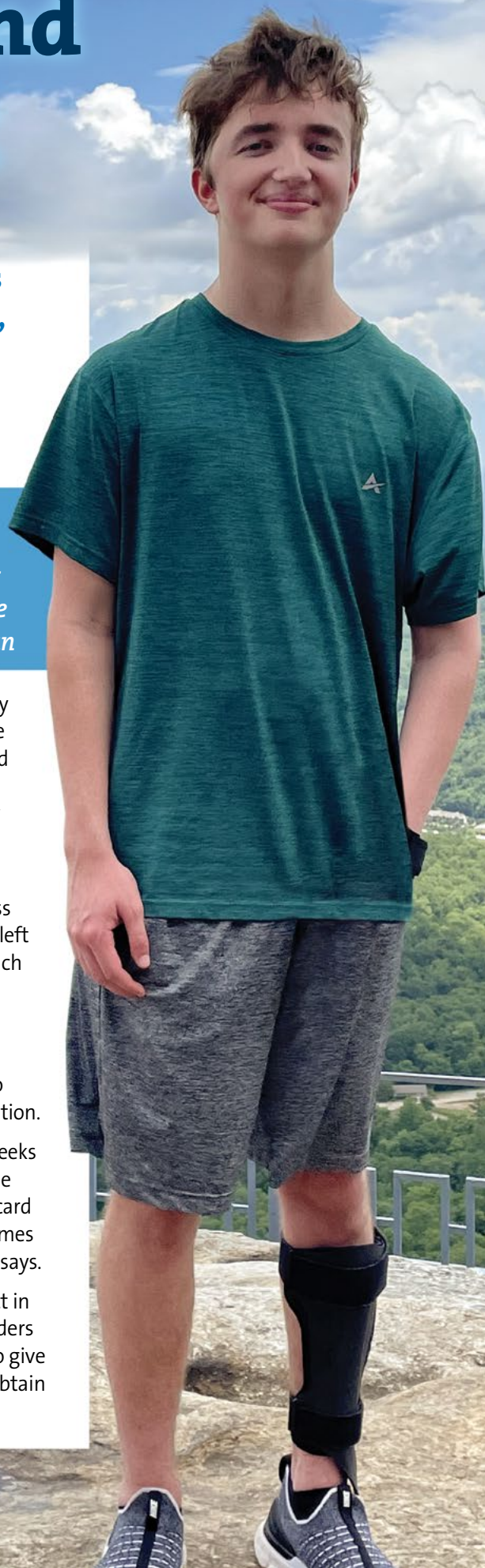
Earlier that summer, he'd experienced a hemorrhagic stroke caused by the rupture of an arteriovenous malformation (AVM), an unusual tangle of arteries and veins in his brain. He'd had the AVM all his life, but it had gone undetected until the rupture. An ambulance rushed him to a hospital near his home in Virginia, where he underwent brain surgery and clinicians worked around the clock to keep him alive.

Once he'd stabilized, he went to Kennedy Krieger Institute's inpatient hospital for two months of rehabilitation. He had significant weakness on the left side of his body, and struggled initially to walk and use his left arm and hand. But the many hours of rehabilitation therapy he did each day soon started to pay off.

He also found the activities offered by the Institute's Child Life and Therapeutic Recreation Department to be particularly helpful. The department's specialists ensured Ethan had plenty of activities to do that were suited to older teens and which would help in his rehabilitation.

Card games had always been a favorite activity for Ethan, but in the weeks following his stroke, he wasn't able to hold the cards in his hands. So he used a wooden card holder to hold his cards for him. Bonus: With the card holder, no one else could see his cards. "The card holder let me play games with my therapists and family, rather than just watch others play," he says.

Ethan and his dad had an idea: What if Ethan could organize a project in which he and his fellow Boy Scouts could make a few dozen card holders and donate them to the department? It would be a wonderful way to give back and help others, and as a service project, would qualify him to obtain the rank of Eagle Scout.



'He Just Took the Experience and Turned It Around'

Ethan progressed from using a wheelchair, to using a walker, to kicking a soccer ball around with his therapists. "He was incredibly motivated to get better," says neuropsychologist Dr. Megan Kramer. "We taught him strategies to help him attend to his left side, and he incorporated them into his therapies. He was very engaged, asking questions to learn more about his condition. And his family was dedicated to helping him recover and were by his side, cheering him on."

Ethan also started planning for the card holder project, sharing his ideas with Brittany Welsch, his therapeutic recreation specialist, who also became his sponsor for the Eagle Scout project.

"I helped him gather the information he'd need to get credit for the project," she explains. "Part of my job is to help patients be ready to reintegrate into their community, and this paired nicely with helping him with the Eagle Scout project. I want my patients to be thinking about life after discharge, and that's exactly what he was doing."

Speech-language pathologist Kristy Chao helped Ethan organize and develop the plan for the project. While the stroke didn't affect Ethan's speech, it did impact his executive functioning. Organizing the project's plan helped Ethan redevelop those skills again. Speech-language pathologists often help patients with skills like organization and prioritization, and these sessions were key to Ethan's cognitive recovery.

Ethan was also thinking about school—he wanted to graduate on time. The school year started while he was still in the hospital, and classes were held virtually, due to the pandemic. In mid-September of 2020, he was discharged from Kennedy Krieger's hospital, then underwent a second brain surgery. In mid-October of that year, soon after recovering from surgery, Ethan started as a patient of the Institute's Specialized Transition Program (STP), a neurorehabilitation day hospital, doing several hours of therapy a day. In the late afternoons and evenings, he'd watch pre-recorded lectures and do his homework.

Because of pandemic-era restrictions on how many people could be at STP in person at one time, Ethan was on-site at STP for three days a week, and did virtual therapies from home on the other two weekdays. Virtual therapies also gave Ethan a little more time to do his schoolwork, as traveling to and from Kennedy Krieger was about a five-hour round-trip.



At STP, Ethan worked with educational specialist Ali Adler and speech-language pathologist Lynnley Moore on strategies to regain his organization skills, and to advocate for himself when in need of additional assistance. Adler also worked with him and his teachers on developing and implementing an individualized education program (IEP). Neuropsychologist Dr. Danielle Ploetz evaluated Ethan's thinking skills and wrote a report for him to share with his teachers that included accommodations to help maximize his learning potential. Ethan's hard work paid off, and he graduated in the spring of 2021. He's now in college, and considering business school and possibly a future in real estate.

"Ethan worked really hard his senior year," Adler says. "I just found him incredible. He was so resilient and diligent, and dedicated to his studies, despite all the challenges." Moore adds, "He worked hard and applied the strategies quickly. He just took the experience and turned it around."

'A Positive Out of Something Very Challenging'

These experiences helped Ethan learn resilience at a young age. He never gave up on himself, or on the idea of giving back.

Shortly before his 18th birthday, after he'd finished at STP, he led a dozen of his fellow Boy Scouts in making card holders for the Institute's Child Life and Therapeutic Recreation Department. When he returned to Kennedy Krieger to deliver the card holders, Welsch was so happy to see how much he'd progressed.

The card holders are used by the department on a daily basis. "They normalize adaptive play without bringing attention to it, and they'll hold up for years," Welsch says. "It was so great to see how Ethan was able to personally give back after overcoming his injury. He made a positive out of something very challenging. A card holder is so simple, but it can really help someone reintegrate back into the community, and Ethan has helped so many kids be able to do just that."

"I'm so grateful for all that Kennedy Krieger did to help me," Ethan says. "It felt really good to be able to give back." —LT

Visit KennedyKrieger.org/CLTR for more information about the Institute's Child Life and Therapeutic Recreation Department.

Astronomical Gains

A DEDICATED TEAM OF CLINICIANS WORKS CLOSELY WITH DANIEL AND HIS FAMILY TO GIVE DANIEL THE SKILLS HE NEEDS TO EXPRESS HIMSELF AND BE THE PERSON HE WAS MEANT TO BE.



DR. JOANNA BURTON WILL NEVER FORGET

that October day in 2018 when she received an urgent phone call from the mother of one of her patients.

Daniel, then 3, was no longer experiencing near-constant seizures, his mom, Dr. Chani Simhi, said.

He'd had an average of at least 40 seizures a day for the first three-plus years of his life—"those are the ones we could count," Dr. Simhi says—but all of a sudden, the seizures subsided. Would it be possible for him to start intensive therapy at Kennedy Krieger Institute as soon as possible, while his seizures remained at bay?

Elated for Daniel and his family, Dr. Burton answered at once: "Of course!"

Daniel was born with a cervicomedullary arteriovenous fistula—a dense knot of blood vessels in his brain stem that can put pressure on the brain and lead to seizures and brain malformations, explains Dr. Burton, a developmental neurologist. He also has linear nevus sebaceous syndrome, a rare disorder that affects systems and organs throughout the body. The seizures delayed Daniel's development, and for the first few years of his life, he was mostly nonverbal and had trouble moving the left side of his body. But once he was no longer seizing throughout the day, amazing things began to happen.

"This was an incredible window for him to finally access learning and his environment," says developmental neuropsychologist Dr. Gwendolyn Gerner, who along with Dr. Burton co-directs the Institute's Infant Neurodevelopment Center, where Daniel received evaluations, recommendations and follow-up care as a baby and toddler.

"He was finally able to pay attention to a task," to be able to complete a full therapy session, and benefit from it, Dr. Burton explains. "We did not want to miss this opportunity."

Dr. Burton made a quick call to Kristine Mauldin, the nurse case manager for the Institute's Specialized Transition Program (STP), a neurorehabilitation day hospital. Within 10 days, Daniel was enrolled in the program. For six weeks, he had two hours of physical, occupational and speech therapies every weekday—just the right amount of therapy recommended for him at the time, Mauldin explains.

Giving Daniel the World—Through Words

Daniel still receives these therapies throughout the year, through Kennedy Krieger's outpatient therapy programs and Community Rehabilitation Program (in which a therapist visits a patient in the patient's home), as well as at school.

Speech-language pathologist Mary Boyle has worked with Daniel for more than three and a half years in outpatient appointments, both in person and via telehealth. When she first met Daniel, he only knew a few words. But within a year and a half, he was understanding English, Spanish and Hebrew, and starting to communicate in all three.

Boyle helped Daniel build up his vocabulary and learn how to put words together to make sentences, ask questions and talk

about his feelings. They worked on storytelling and recounting stories, and on scripts—how to ask an adult for help, for example. "In three years, he's gone from not talking, to telling simple sentences, to using three to five sentences sequenced together to tell stories and talk about himself," Boyle says. "It's remarkable."

Daniel still has seizures, but usually only one or two a day, and they're brief, explains Daniel's neurologist, Dr. Eric Kossoff, who directs Johns Hopkins Medicine's Child Neurology Residency Program. Now his body responds to epilepsy medication, which hadn't been the case during the first few years of his life. Dr. Kossoff checks in with Daniel's parents periodically to be sure Daniel's medications are working well and to tweak the dosage, if needed.

Being able to use language to communicate also means Daniel has the ability to talk about the seizures, and can advocate for himself. That will make it easier for him to gain independence and agency in his medical care as he grows up.

"It will also help him not be scared of his seizures," Boyle says. "They're not something we don't talk about. We must give him the language to talk openly about his seizures, and the feelings he has about them. We need to talk about how the seizures are a part of who he is, without any judgment, and that will allow him to feel that he is whole, just as he is."

Coming Into His Own

Daniel has also worked closely with occupational therapist Sapna Bansil, both in person and via telehealth. When she first met Daniel, in early 2019, he had very limited speech. But at a recent therapy session, "He was telling me everything he ate that day, and about his friends at school," she says. "His infectious personality is on full display. He's energetic, talkative, sweet and friendly—it's been really wonderful to see his personality emerge. He really has come into his own."



In her earliest sessions with Daniel, Bansil worked on very basic motor skills with him, doing things like putting together a puzzle. More recently, they've been working on drawing shapes and cutting them out with scissors, as well as coloring and writing—skills he uses to succeed in school.

When Daniel was 4, Dr. Burton and Dr. Gerner jointly evaluated him, through the Institute's Center for Development and Learning and Department of Neuropsychology respectively, to see what his needs would be in the classroom. "We found clear evidence that Daniel could learn in a highly structured environment," Dr. Burton says. That evaluation helped Daniel's parents find just the right school for their son, one that would provide him with exactly the right amount of support he needed to learn and grow. Since then, Daniel's team at Kennedy Krieger has worked with the school to ensure his medical and learning needs are met each day. This fall, he starts second grade.

Great, Great Strides

Now 7, Daniel cracks jokes, loves playing with his sisters, and enjoys going to school, his mom says. "He's super social, loves talking, loves basketball and playing with toy cars and balls, loves jumping on the trampoline and playing outside and riding his scooter, and is super, super loving."

Daniel's parents once wondered if their son would be able to communicate. "But he is talking, and he's very expressive, and he's making great, great strides," says his mom, who is teaching him how to read in Hebrew. "I'm hopeful that when he's 13, he'll be able to have a bar mitzvah, because he can read Hebrew. We were so worried he might not be able to have opportunities like that."

"It takes so many people from such a wide range of fields to make him who he is. Lots of people have had such a great impact."

– Dr. Chani Simhi, Daniel's mom



"I'm in incredible awe of Daniel and what he has accomplished over the years," Dr. Gerner adds. "Every point along the path that I've seen him, he's made astronomical gains."

Daniel also receives care from ophthalmologist Dr. Michael Repka, vice chair for clinical practice at Johns Hopkins Medicine's Wilmer Eye Institute. "We're working to optimize his vision," Dr. Repka explains. Daniel has had eye surgery to help his eyes coordinate with each other, and for a brief time, he wore a patch over his left eye, to strengthen the development of his right eye.

"So many different parts of the Kennedy Krieger-Johns Hopkins community were able to come together, at the right time, and help him get to where he is now," Dr. Burton says. "At each stage of his development, we were able to give him just what he needed to make the next leap. No one department could have done that, nor could he have done that without the help of his parents and community."

"It takes so many people from such a wide range of fields to make him who he is," his mom says. "Lots of people have had such a great impact."

"Having patients like Daniel is incredibly humbling," Dr. Gerner adds, "because you realize it's a combination of the whole team coming together, plus Daniel's persistence and determination, that's made all the difference." – *LT*



Visit KennedyKrieger.org/INC to learn more about the Institute's Infant Neurodevelopment Center, and visit KennedyKrieger.org/STP to learn more about the Institute's Specialized Transition Program.

Daniel with Mary Boyle (left) and Dr. Gwendolyn Gerner

Technology for Independence

At Kennedy Krieger's Assistive Technology Clinic, patients are matched with the tools and technologies they need to make their way in the world—and their voices heard.

“It’s all about independence.”

That’s how Lauren Tooley, a speech-language pathologist, describes the mission of Kennedy Krieger Institute’s Assistive Technology Clinic, which she manages. “We work to ensure patients have what they need to go about their day, at home, school, work and in the community, as independently as possible. It’s not about changing what patients do, but about accommodating them in what they want to do and making sure they have the right tools for it.”

The clinic, which has been serving patients and families for more than 30 years, is staffed with three speech-language pathologists and two occupational therapists. They work with patients to identify needs in communication, reading, spelling, mobility, and phone, computer and environmental access—turning lights on and off in a room, for example. They also match, customize, and fit or program new equipment, devices and technologies for patients.

Initial evaluations typically last two hours, and are offered throughout the week. Follow-up evaluations and appointments help clinic staff members narrow down the best technology for each patient—be it a complex power wheelchair, a communication device that uses pictures for words, eye-gaze equipment that allows one to type out an email by looking at a special keyboard, or something else, or a combination of things. Patients and their families have the opportunity to test out different pieces of equipment to make sure they choose the right products.

“It’s not about changing what patients do, but about accommodating them in what they want to do.”

– Lauren Tooley

*Clockwise, from top left:
Laura Dickerson,
Susan Schiaffino,
Alexis Tutor,
Emma Martin and
Lauren Tooley*

Giving Patients a Voice

One of the clinic’s most requested services is assistance with augmentative and alternative communication (AAC), Tooley says. An individual who is nonspeaking can select pictures or words on an AAC device, or spell a word—perhaps with a finger or an eye-gaze tracker—and the device will say that word out loud. AAC devices are essential to giving individuals who are nonspeaking a voice in the community.

When it comes to training patients and families to use new devices, several appointments may be needed, especially for communication devices. “We train a patient’s family members, too, so they can model using the device for everyday communication,” Tooley says. “We also train them on adding new words to the device—siblings are particularly good at that, especially when parents are intimidated by the new technology.”

Modeling using new communication equipment, Tooley explains, is particularly important for children, as they learn language by being around others using that language and method. “We’re giving patients a way to communicate that isn’t often used in the community or with those around them,” she says. “But if family members and caregivers model communication on an AAC device, that mode of communication will soon become functional and relevant for the patient—and their family.”

As a speech-language pathologist, Tooley is well-situated to help patients find a communication style and method that work for them. “For young patients in need of AAC, we want to be sure they’re learning language and communication skills while using their new AAC device,” she says. Individuals who’ve experienced a loss of oral speech or language due to a brain injury or aphasia, for example, may have a different set of needs—and a different set of possible technological solutions, she explains.

While most of the clinic’s patients are children and teens, the clinic sees people of all ages. Some have been coming to the clinic for many years, receiving new evaluations as their needs change and as technology offers new options for accessibility. “We’re here to help individuals of any age find the right technologies to help them be as independent as possible, and to live their lives to the fullest.” – LT

Visit [KennedyKrieger.org/ATC](https://www.kennedykrieger.org/ATC) to learn more about the Institute’s Assistive Technology Clinic.

A CALLING AND A PROMISE

By Ariel Obioma Egbunine



Ariel spent more than two months at Kennedy Krieger as a tiny infant. Now, she is preparing for a career in medicine to help others.

The earliest moments of my life brought my family and me face to face with the limits of scientific knowledge and our understanding of the complexities of human health. I was

born via cesarean section in 1999, after doctors detected

I wasn't moving and was in perinatal distress while still inside my mother's womb. Unresponsive and cyanotic, I had an Apgar score of only 2 (out of 10). My father recalls whispers of brain death circulating the room.

Chest X-rays and echocardiograms revealed a hole in the wall between the upper chambers of my heart, which was dangerously enlarged and not functioning properly. I was diagnosed with persistent pulmonary hypertension and meconium aspiration and was in dire need of a venoarterial extracorporeal membrane oxygenation (VA-ECMO) machine to do the work of breathing for me.

There was no VA-ECMO machine at the hospital where I was born, but there was one at The Johns Hopkins Hospital, not too far away. I was immediately transferred to Johns Hopkins' pediatric intensive care unit, where my care team was led by Dr. Ivor Berkowitz, a former clinical director of the unit. He placed me in a medically induced coma for four days and provided me with complete cardiac and respiratory life support via the VA-ECMO machine.

“I am laser-focused on developing the skills necessary to change the life trajectory of others, just as Dr. Berkowitz and Dr. Lipkin and a host of other practitioners did for me when they answered the call.”

– Ariel Egbunine



Once stabilized, I spent the next 68 days at Kennedy Krieger Institute's inpatient rehabilitation hospital, under the care of Dr. Paul Lipkin, who now directs the Institute's medical outpatient services. That was followed by two years, seven months and four days of weekly appointments, scans and therapies, many of which took place at the Institute's outpatient center.

While early neurodevelopmental exams revealed mild delays in my gross motor skills, I was later found to be displaying age-appropriate functioning. By my first birthday, my cardiac and other medical abnormalities had self-corrected. However, we still didn't know what had happened to me in utero. Thus, I set out on a mission to find the answer to this unsolved mystery.

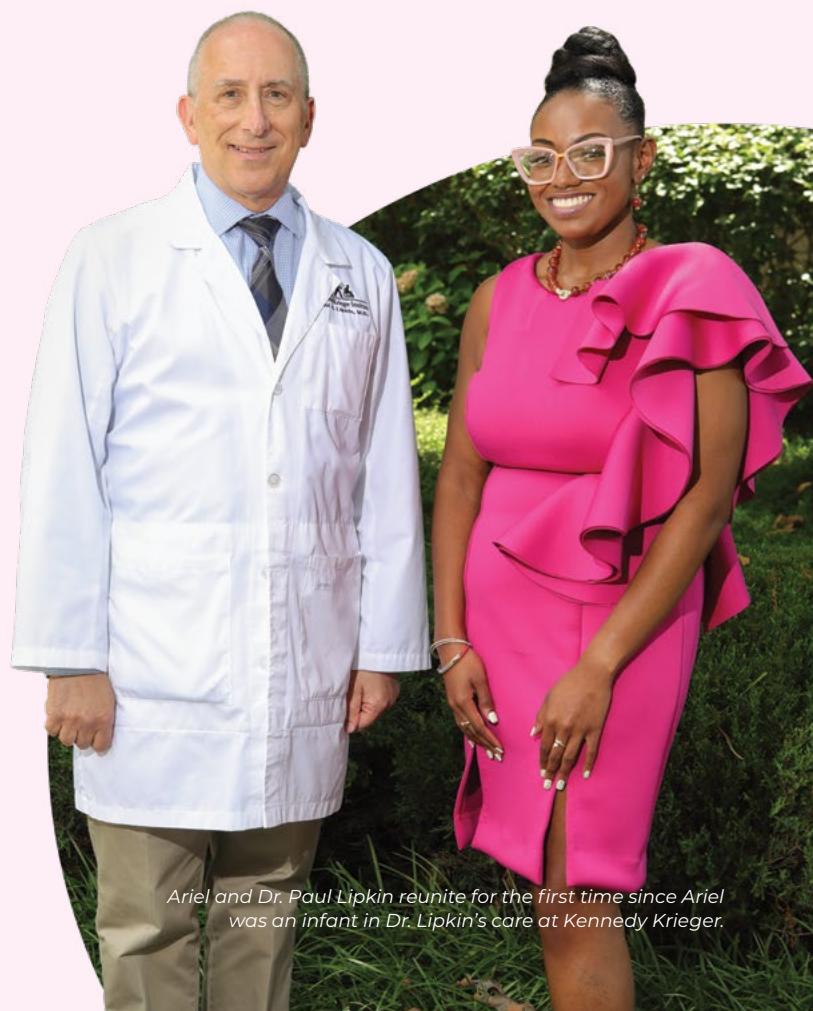
Reviewing my clinical notes and speaking candidly with my parents about my birth and early years instilled in me two core values: a desire to advance our medical knowledge to assist in providing resolution in the face of uncertainty, and a promise to apply that knowledge to serve those in need. Driven by these core values, I have committed my future to the study of medicine, embarking on a personal journey dedicated to servant leadership to help underserved families and populations.

While attending middle school at Roland Park Country School in Baltimore, I was invited to join the school's STEM Institute. One of the program's requirements was to complete a yearlong internship in a STEM (science, technology, engineering and math) field during my junior year. With the promise I'd made to help others at the forefront of my mind, I contacted The Johns Hopkins Hospital's ECMO team to ask about internship opportunities. The physician who embraced my passion and took time to listen to my aspirations was none other than Dr. Berkowitz. With more than a decade since our last meeting, Dr. B. was in awe as I stood before him, healthy, happy and smiling—what an unbelievable reunion!

Since graduating from the University of Maryland, Baltimore County, where I studied biochemistry and molecular biology, I've worked as the research coordinator for the Johns Hopkins Children's Center's Pediatric Anesthesiology and Critical Care Medicine team. I worked with nurses and physicians to implement various novel medical techniques into patient care regimens. In August, I began medical school at St. George's University School of Medicine, the next step on my way to becoming a pediatric anesthesiologist.

I firmly believe that anyone who provides intensive care must care intensely, with passion, integrity and trust. This ethos has sustained my growth and fortified my desire to have a profound and positive impact on every life I'm fortunate to touch. The satisfaction I receive from helping others is fulfilling and invigorating. I am laser-focused on developing the skills necessary to change the life trajectory of others, just as Dr. Berkowitz and Dr. Lipkin and a host of other practitioners did for me when they answered the call. Critical care medicine, with a specialty in the field of pediatric anesthesiology, is the cornerstone of my foundation upon which I will continue to build. It's my calling—and my promise.

Visit [KennedyKrieger.org/INC](https://www.kennedykrieger.org/INC) to learn about the Institute's Infant Neurodevelopment Center, which provides medical care to infants who have been discharged from neonatal intensive care units.



Ariel and Dr. Paul Lipkin reunite for the first time since Ariel was an infant in Dr. Lipkin's care at Kennedy Krieger.



Merging Psychology and Neuroscience

The research team at the Institute's Research Neurophysiology Laboratory is using advanced EEG technologies to search the brain for clues to diagnoses like autism and ADHD.



“Ultimately, we hope to be able to use these biomarkers to complement psychology testing... to get a fuller picture of a person’s brain.”

– Dr. Joshua Ewen

With every electrode they place on someone’s head, the research team at Kennedy Krieger Institute’s Research Neurophysiology Laboratory is one step closer to learning more about how electrical activity in the brain affects things like motor control, inhibition and nonverbal communication.

That’s a lot of information to be gleaned—but also a lot of electrodes.

The team works with children and teens who’ve chosen to participate in clinical studies at Kennedy Krieger. Some participants are neurotypical, while others have brain-based diagnoses such as attention-deficit/hyperactivity disorder (ADHD) or autism spectrum disorder (ASD). Most participants get an electroencephalogram, also known as an EEG—a painless, harmless, noninvasive test that measures electrical activity in the brain, both at rest and while doing things like tapping fingers or imitating gestures.

During the EEG, each participant wears a snug-fitting cap with dozens of electrodes affixed to it. The electrodes “listen” to and record the electrical activity in the brain, allowing the lab’s researchers a detailed glimpse at the brain’s inner workings.

“We’re looking for biomarkers in the brain that indicate how each person’s brain functions,” explains Dr. Joshua Ewen, the lab’s director. “Ultimately, we hope to be able to use these biomarkers to complement psychology testing—or even to get information that psychological tests aren’t able to deliver—to get a fuller picture of a person’s brain, as well as to track their response to brain-based therapies.”

“We’re merging psychology and neuroscience,” adds Michael Levine, a former member of the lab’s research team.

In particular, the team is studying motor control in children and teens with ASD or ADHD. Those with ASD may have difficulty imitating other people’s gestures, affecting their ability to communicate nonverbally, while those with ADHD might have difficulty with inhibition—restraining certain movements while making other movements. The team also studies neurotypical kids and teens as part of a control group.

A Helping Hand

In addition to this work, the lab’s research team also helps other researchers—across Kennedy Krieger and The Johns Hopkins University—use the lab’s EEG equipment. That means prepping the lab, training outside researchers to use the equipment, helping them design their EEG experiments, and assisting with data analysis and interpretation, explains research team member and biomedical engineer Evan Bucklin.

“We’re also looking at new ways to analyze the data—new techniques that can focus on specific questions that might not have been asked before,” says Bucklin, who is analyzing new automated tools for processing EEG data.

“If, with strong proof, the biomarkers we’re looking for were ever to enter clinical practice, then these automated tools will greatly help people around the world,” Dr. Ewen adds.

But to get to that point, Dr. Ewen and his team need time—and participants. “We want to answer as many questions about the brain as we can, as rigorously as we can, and as quickly as we can, and we can only do that if we have high levels of recruitment,” he says. “If someone had a magic wand and asked us what we needed to do that, the answer would probably be: ‘Research participants.’” – LT

Kennedy Krieger is recruiting children and teens, both with and without ADHD and ASD, to participate in research studies. Visit [KennedyKrieger.org/Participate](https://www.kennedykrieger.org/Participate) for more information.

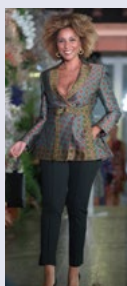


UPCOMING EVENTS

Kennedy Krieger's events are a great way to bring family and community members together!
 Visit KennedyKrieger.org/Events to explore all the exciting things 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.

The Fall Fête 4 | September 23, 2022



Mark your calendars for The Fall Fête 4, a don't-miss fall fashion event benefiting Kennedy Krieger Institute. Green Spring Station will transform into a fashion extravaganza, with a huge outdoor tent and runway featuring fashion highlights from Green Spring Station retailers, local celebrity models, delectable food and beverage stations by Green Spring Station merchants, funky dance music, and plenty of style! Visit KennedyKrieger.org/FallFete2022 for more information.

National Capital Region Security Forum Charity Golf Tournament | October 3, 2022

Join us for the ninth annual National Capital Region Security Forum Charity Golf Tournament. The event will be held at the Mount Vernon Country Club in Alexandria, Virginia, and proceeds will benefit Kennedy Krieger's Center for Brain Injury Recovery. Visit KennedyKrieger.org/NCRSFCharityGolf to learn more.

Barrels & Bonfires

November 3, 2022

Join the Women's Initiative Network for Kennedy Krieger Institute at Farmacy Brewing in Reisterstown for a fun evening of delicious food and music, all to benefit Kennedy Krieger. Visit KennedyKrieger.org/Barrels for more information.

33rd Annual Festival of Trees

The holidays are back, and we need your help!

Kennedy Krieger's 33rd annual Festival of Trees opens its doors in just a few months! 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 so excited to be hosting Festival of Trees in person again this year. To make this our best Festival yet, we need your help! We're looking for individuals and organizations interested in:

- Sponsoring
- Volunteering
- Entertaining visitors
- Donating auction items
- Designing a tree, wreath or gingerbread house

To learn more, email FestivalOfTrees@KennedyKrieger.org or visit KennedyKrieger.org/FestivalOfTrees

November 25–27, 2022
 Maryland State Fairgrounds



Neurodiversity in the Workplace: A Collaborative National Conference

March 22–24, 2023
 Washington, D.C.

Visit KennedyKrieger.org/NDW23 for more information.

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



Make a Difference for Patients and Students at Kennedy Krieger!

Connect your company's brand with helping Kennedy Krieger and the kids we serve. Visit KennedyKrieger.org/Corporate to learn more.

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.



Kennedy Krieger Institute

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Your support helps amazing kids like Daniel.

When you give to Kennedy Krieger Institute, you're helping us pursue every possibility—and beyond—for children like Daniel. Your gift supports groundbreaking education, research and care that bring hope and transform lives. Thank you so much!

Make your donation today! Visit us online at KennedyKrieger.org/PS22 or use the QR code to the right, or mail us your donation using the return envelope inside this issue.



The individualized care that Daniel, 7, receives at Kennedy Krieger allows him to learn, play, grow and thrive. Read Daniel's story on Page 8.



Giving to Kennedy Krieger

WHY WE GIVE



“We give to further Dr. Anne Comi and her team’s research for not only our son Cole, but everyone impacted by Sturge-Weber syndrome. Thanks to her passion and dedication, we worry a lot less about Cole’s chance of seizures, and he spends more time doing what he loves.”

– Bari and Cory Clark

Visit KennedyKrieger.org/SWSResearch to learn more about research on Sturge-Weber syndrome at Kennedy Krieger.