

potential

A publication of Kennedy Krieger Institute Fall | Winter 2019

When Victories Add Up
Rehabilitation Brings
Independence for
Children With AFM

Amazing Spirit

Surgery and Rehabilitation
for Cerebral Palsy

Hanging 110 Percent

Determined to Surf Again
After Brain Injury

Joyful Play

Medical Day Care for Children
With Complex Conditions



Kennedy Krieger Institute



Greetings From Our President

Hello, all,

Our cover story for this issue of *Potential* features children who've been impacted by a devastating, polio-like disorder called acute flaccid myelitis (AFM). You'll read about Ava, Geuko and Ryleigh, and the amazing work they've done with our innovative rehabilitation team to get back to being kids again. Little is known about AFM, but Kennedy Krieger Institute is one of the top places in the world for rehabilitative care for children with the disorder. Our physicians, therapists and researchers are working every day to develop new, life-changing therapies and interventions.

You'll also read about Brayden's drive to surf again after experiencing a brain injury, Journee's first steps following innovative surgery and therapies to counter the effects of cerebral palsy, and more. As you explore the magazine, look for links to online videos that accompany some of the stories. I find these videos about the remarkable children and families we serve to be truly inspiring, and I hope you do, too.

At Kennedy Krieger, we serve children and families in need of our care 24/7, 365 days a year. We never pause our research—we're always striving to find better treatments and possible cures. None of these would be possible without your support, which is vitally important to our mission. Please visit KennedyKrieger.org/YE19 to get involved.

Wishing you the happiest of holiday seasons.

Many thanks,

Bradley L. Schlaggar, MD, PhD
President and CEO

P.S. I welcome your comments, questions and suggestions—email me at CEO@KennedyKrieger.org to get in touch.

On the cover: Geuko received treatment for acute flaccid myelitis (AFM) at Kennedy Krieger earlier this year. Read his story—and those of other children with AFM—on page 8.

INSPIRING POTENTIAL

From Intern to Colleague

After completing an internship through Project SEARCH, Kennedy Krieger High School graduate John Perry landed a full-time job at Kennedy Krieger.

3

FEATURES

Hanging T10 Percent

A brain injury paralyzed Brayden from the neck down, but comprehensive rehabilitation has him back on his feet again.

4

Amazing Spirit

When doctors told Journee's parents their daughter would likely never see, talk or walk, they refused to believe them. Journee has done all that, and more.

6

When Victories Add Up

For children with AFM, rehabilitation and recovery can be intense. The independence they gain back makes all the difference.

8

PROGRAM SPOTLIGHT

Thriving Through Joyful Play

PACT provides children with specialized medical care and inclusive learning experiences that positively impact them and their families for years to come.

12

RESEARCH FRONTIERS

Identifying Trauma in Children With Autism

A new tablet-based app developed at Kennedy Krieger makes it easier to assess children with autism spectrum disorder for trauma.

14

NEWS & EVENTS

A summary of upcoming events—and a wrapup of recent ones—at Kennedy Krieger.

15

POTENTIAL

EDITOR

Laura Thornton

CREATIVE SERVICES MANAGER

Sarah Mooney

DESIGNERS

Tom Czajkowski, Amy Mallik
and Erin Parsons

PROOFREADER

Nina K. Pettis

PHOTOGRAPHY

Rachel Morgan and Robin Sommer

AVP MARKETING, PR AND COMMUNICATIONS

Lisa Nickerson

MEDIA INQUIRIES

Stacey Bollinger

PUBLICATION INQUIRIES

443-923-7330 or TTY 443-923-2645

For appointments and referrals, visit
KennedyKrieger.org/PatientCare or call 888-554-2080.

Potential is published by the External Relations Department of Kennedy Krieger Institute, 707 North Broadway, Baltimore, Maryland 21205. Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Kennedy Krieger Institute provides care that preserves cultural, psychosocial, spiritual and personal values, beliefs and preferences. Care is free from discrimination based on age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression, including transgender. We encourage patients and families to become active partners in their care by asking questions, seeking resources and advocating for the services and support they need.

Email us at PotentialMag@KennedyKrieger.org to update your contact or mailing information. Send an email to Unsubscribe@KennedyKrieger.org or visit KennedyKrieger.org/Unsubscribe to unsubscribe from future Kennedy Krieger Institute communications.

©2019, Kennedy Krieger Institute

Visit PotentialMag.KennedyKrieger.org
for more inspiring stories, news and updates.

FROM INTERN TO COLLEAGUE

After completing an internship through Project SEARCH, Kennedy Krieger High School graduate John Perry landed a full-time job at Kennedy Krieger.

As an inventory technician at Kennedy Krieger Institute, John Perry spends much of the workday stocking, packing and delivering supplies to various departments at Kennedy Krieger. But his favorite part of the day doesn't involve inventory at all.

"I love working in the parking garage," says Perry, 22, who has autism spectrum disorder. "I love cars. Mustangs are my favorites."

Perry graduated from Kennedy Krieger High School's certificate program this past June. During his last year of school, he participated in Project SEARCH, an internship program for young adults with neurodiverse traits. He interned with different departments at the Institute and attended professional development classes. The Institute's Facilities Department hired Perry at the end of the program.

"We had a position open for our inventory control team. John had interned with us during Project SEARCH, so we knew he could do the job," explains inventory technician Shawn Fallin, Perry's mentor.

But of all the internships Perry did during Project SEARCH, he most enjoyed picking up trash in Kennedy Krieger's

Broadway Campus parking garage, and "I didn't want to take that away from him," Fallin says. So every afternoon,

Perry takes a break from delivering supplies and heads over to the garage to keep it looking tidy. It's the perfect midday assignment for Perry.

Top: As an inventory technician at Kennedy Krieger, John Perry stocks, packs and delivers supplies to various Institute departments. Bottom: Inventory technician Shawn Fallin (left) is Perry's mentor.



Since joining the Facilities staff, Perry has impressed everyone with whom he's worked. Fallin initially accompanied Perry on deliveries, but Perry soon started making deliveries on his own. One day, Fallin received a call from a department to which Perry had recently delivered supplies. "They liked John so much, they wanted to know if they could contact him directly for their supplies!"

"John always has a smile on his face and is always very excited to work," says Bayadir Mohamed-Osman, an employment training specialist with Project SEARCH. "His personality shines through whatever he does—and he always remembers what kind of car I have."

When Mohamed-Osman gives Perry feedback, "he incorporates that into his job," she says. "He takes initiative and brings the feedback up the next time we meet. I'm really proud of him, and of how he's become such a great employee and colleague."

Perry is one of six staff members hired by Kennedy Krieger since 2018 through the Institute's HR Pathways Hiring Program, part of the Institute's Neurodiversity at Work initiative. Three are mentored by Kennedy Krieger's CORE Foundations program, which supports individuals with neurodiverse traits working at Kennedy Krieger and in the community.

"I've been so impressed by John's growth as a professional," says Rebecca March, EdD, Project SEARCH coordinator. Perry's ability to be independent—scheduling his own rides to work and taking ownership of his job duties—has been the most significant change she's seen in him. "All of these independent tasks have allowed John to become more confident and feel successful."

"John's attitude is always very positive, and he's a great colleague," Fallin adds. "Working with him has helped me better understand individuals with autism—and that's living the mission of Kennedy Krieger." – *LT*

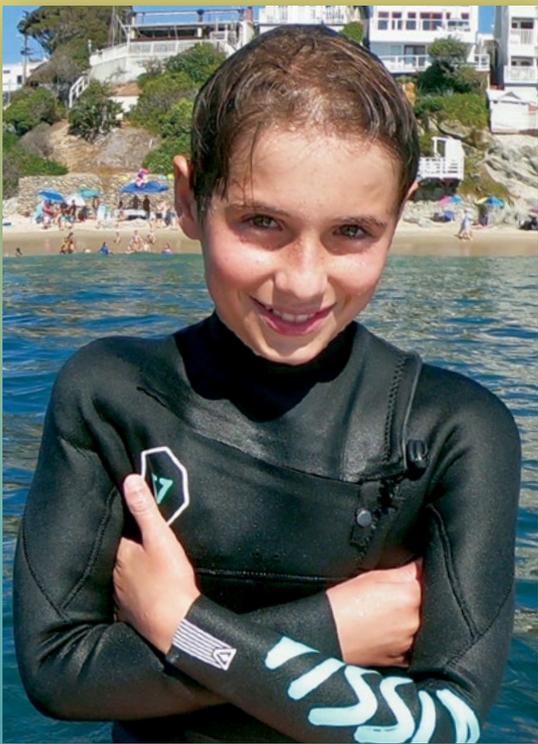
Visit [KennedyKrieger.org/Neurodiversity](https://www.kennedykrieger.org/Neurodiversity) to learn more about Kennedy Krieger's HR Pathways Hiring Program, Neurodiversity at Work initiative, Project SEARCH and CORE Foundations.

"All of these independent tasks have allowed John to become more confident and feel successful."

– Rebecca March,
Project SEARCH coordinator



Hangin' 110 PERCENT



A brain injury paralyzed Brayden from the neck down, but comprehensive rehabilitation has him back on his feet again.

As Brayden snowboarded down Oregon's Mt. Bachelor on February 20, 2018, he was already enjoying a little taste of the kind of success that comes only with many hours of hard work.

Just 11 years old, he'd recently won the under-13 division of a surfing contest in his hometown of Laguna Beach, California, and was looking forward to going pro. A surfer through and through, he'd taken his skills to the slopes that day, and with each trip down the trail, he aimed a little higher on the jump. That's the kind of young man Brayden is—always working hard to get better.

But after he landed the last jump of the day, he fell down. "When I caught up to him, he was just lying there, lifeless," says his dad, Matt. "His eyes were in the back of his head. No pulse. No breath. If I didn't give him CPR, he could have died."

A rescue team airlifted Brayden to a nearby hospital, where he remained in a medically-induced coma for three weeks, his brain badly injured from the fall, his body paralyzed from the neck down. Doctors cautioned that the paralysis could be permanent. But Brayden wasn't giving up without a fight, and soon began the long process of relearning how to talk, eat, walk and use his arms and hands.

"He's very dedicated to whatever he does," explains his mom, Denise. "He is a hard worker. Give him a push, and he just keeps going."

Brayden spent four months in inpatient rehabilitation in Oregon, then went home and began outpatient therapy, sticking with it like any athlete determined to win. His walking improved, as did the use of his left arm, but his right arm remained immobile.

Suspecting dystonia, which can result from a brain injury, his parents brought him to Kennedy Krieger Institute for constraint-induced and bimanual therapy (CIBT), in which the stronger arm is put in a hard cast—shoulder to fingertips—during therapy, forcing the weaker arm to fully engage in therapy exercises. It's just one of the many types of therapeutic treatments for which Kennedy Krieger is well known.

The Right Diagnosis

During Brayden's initial evaluation at the Institute, occupational therapist Lindsey Harris noticed that Brayden's right shoulder was completely frozen. With dystonia, there would have been at least some movement—it just wouldn't have been controlled.

It turned out that in the snowboarding accident, he'd fractured one of the bones in his shoulder, as well as his wrist, probably from landing on his outstretched arm, Harris explains. That had gone undiagnosed, and scar tissue had healed over his shoulder joint, a condition called adhesive capsulitis, keeping his right arm from benefiting from therapy.

Surgery with Johns Hopkins pediatric orthopedic surgeon Dr. John Tis would be needed to free Brayden's shoulder joint, but "I don't care how big the needles are," Brayden said. "I promise, when I wake up, to give everything I have and 110 percent on my rehab."



After the surgery, Brayden completed three to five hours of intense therapies a day for nearly three months at Kennedy Krieger’s day hospital, part of the Institute’s Fairmount Rehabilitation Programs, rehabbing from both the surgery and the brain injury. This past summer, Brayden returned for two more months of daily rehabilitation at the day hospital.

Comprehensive Rehabilitation

Over the course of the two admissions, Brayden improved his balance and overall strength, and his ability to walk and use his arms, especially his right arm, with which he did CIBT during his second admission. Active video games had Brayden doing things like playing virtual tennis on one foot to work on his balance. Harris got out a scooter board, so Brayden could mock-surf down the hall.

Vestibular testing revealed that Brayden was having difficulty focusing on a target during activities that also required head movement. This was impacting his balance as he walked, says physical therapist Dr. Katlyn Billups. To retrain the connections between Brayden’s eyes and brain, Dr. Billups would hold up a card with a smiley face on it, and Brayden would shake his head while keeping his eyes on the face.

“Initially, he could only do five to 10 seconds of that, but by the end of his second admission, he was able to keep it up for a minute,” Dr. Billups says.

Above: Brayden uses a Bioness device while walking on a treadmill during physical therapy at Kennedy Krieger. The device delivers functional electrical stimulation to Brayden’s right leg to improve his gait.



Above: Brayden’s left arm is immobilized in a removable cast during a constraint-induced and bimanual therapy session at Kennedy Krieger with occupational therapist Lindsey Harris.

Right: Brayden mock-surfs down the hall at the Institute’s day hospital.



Left: Brayden works with educational specialist Alecsandra Adler between therapy sessions at Kennedy Krieger’s day hospital.



Brayden’s rehabilitation addressed more than just movement. Speech-language pathologist Brynn Schor helped Brayden redevelop his memory. To help him recall words, Schor encouraged him to describe the word he was trying to remember. Together, they worked on strategies to help Brayden break down complex sentences and directions, and problem-solve.

Between therapy sessions, Brayden worked with educational specialist Alecsandra Adler, who discovered that Brayden did well in a small class setting, with plenty of breaks and specific strategies to help him concentrate. Adler prepared recommendations for an individualized education plan for Brayden’s teachers to follow to ensure he would continue to succeed in school.

And neuropsychologists Dr. Natasha Ludwig and Dr. Danielle Ploetz worked with Brayden to develop a list of strategies—e.g., “calm down,” “take a break”—that he could use when he felt frustrated. At first, he needed cues to use the appropriate strategy, but by the end of his second admission, he knew exactly when and how to apply them.

Since returning to California, Brayden’s kept up with therapies, both at home and with a local physical and occupational therapy provider, where he goes four times a week. “Thanks to all the therapy he’s done, he’s able to hang out at the beach with his friends again,” his mom says.

Of course, what he really wants to do is surf. And with Brayden’s determination knowing no bounds, Laguna Beach may not have long to wait before seeing him take to the waves again. – *LT*

Visit KennedyKrieger.org/DayHospital and KennedyKrieger.org/CIBT to learn more about our day hospital and CIBT program.

“Every time Brayden goes to Kennedy Krieger, he just gets stronger and stronger, improving by leaps and bounds. It’s an amazing place.”

– Denise, Brayden’s mom



Amazing Spirit

Two surgeries, intense rehabilitation and one determined little girl add up to Journee's remarkable progress.



When doctors told Journee's parents, Antwonn and Ebony, their daughter would likely never see, talk or walk, they refused to believe them.

"We told the doctors that Journee would do all of that, and more," Ebony says. "If you have faith and believe in your child's ability to overcome obstacles, they will surprise you."

Journee, 5, was born with spastic cerebral palsy, a condition of extreme muscle tightness often resulting from an injury to the brain. Journee's earliest days were difficult, but her parents were determined to find treatment that would reduce her spasticity and support her cognitive and emotional development.

From the start, and with her parents' support, Journee defied doctors' predictions. At only a year old, Journee was thriving, meeting her verbal and physical milestones, surprising everyone with her near-perfect eyesight, and using her bright purple walker to explore her surroundings.

But because of her extreme spasticity, her knees wouldn't straighten and she couldn't flex her ankles. Journee walked on the tips of her toes—like an elegant ballerina, she said—but with a scissored gait, one foot crossing in front of the other. About 75 percent of the time, she needed a wheelchair for mobility.

Two Surgeries

Two years ago, Ebony's research led her to Johns Hopkins pediatric neurosurgeon Dr. Shenandoah Robinson and the Johns Hopkins-Kennedy Krieger Institute spasticity management team. Dr. Robinson is one of only a handful of neurosurgeons in the country performing selective dorsal rhizotomy, also known as SDR, to help relieve spasticity. In this neurosurgical procedure, Dr. Robinson makes a small incision in a child's lower back, locates abnormally firing nerve rootlets at the base of the spinal cord, and selectively snips them, leaving normally firing rootlets intact.

In February 2018, Ebony and Journee traveled from Boston to Baltimore to meet with Dr. Robinson, rehabilitation physiatrist Dr. Frank Pidcock, Johns



Hopkins pediatric orthopedic surgeon Dr. Ranjit Varghese, and the other members of the spasticity management team. “We could tell she was very motivated to walk,” physical therapy manager Janice Laux says, “but we could also see that walking was very fatiguing to her, because her leg muscles were so tight.”

So tight, in fact, that before SDR surgery, Journee needed orthopedic surgery, explains pediatric nurse practitioner Colleen Lenz. The next month, Dr. Varghese, who also serves as Kennedy Krieger’s medical director of ortho-cerebral palsy, made small incisions to the tendons in Journee’s legs—just enough to lengthen them and relieve some of the tightness. Six months later, Journee returned to Baltimore for SDR surgery with Dr. Robinson, followed by two months of intense therapies at Kennedy Krieger’s inpatient rehabilitation hospital.

Defying Expectations

Because SDR immediately changed the muscle tone of Journee’s legs, she needed to learn “how to use her legs again, and how to walk with a nice gait pattern,” Dr. Robinson explains.

“Initially, we were doing very basic hip and trunk strengthening, to get Journee to a point where she could take her first steps with her muscles moving in the right way,” explains physical therapist Alissa Marzetti. Kneeling at a bench, Journee would play with princess dolls, helping them get ready for a ball, while strengthening her core and hips and having fun at the same time.

When it came time to relearn how to walk, Journee did a lot of gait training, often using the Institute’s G-EO System, robotic technology that moved her feet through the correct walking motions while suspending her in a harness. By the time Journee returned to Boston, she was walking with her walker, with the correct gait pattern, for up to 200 feet, and could stand for a full 15 seconds—something Journee’s family was once told would never happen.

Because cerebral palsy had also affected movement in her hands and arms, Journee worked on a variety of developmentally appropriate tasks, such as how to get dressed and use scissors, with occupational therapist Scott Frampton. “She made such a good effort, even when things were challenging,” Frampton says.

Journee’s positive and determined approach to life made a big impression on everyone she met at Kennedy Krieger. “She’s got a really magnetic personality that draws everyone in, whether you’re working with her or not,” Frampton explains. “There’s no way to work with her without constantly having a big smile on your face.”

Journee also received educational support during her inpatient stay. “Journee really missed going to school, and the educational activities motivated her and kept her on pace with her classmates back home,” Ebony says.

Far left: Journee walks down the hall at Kennedy Krieger. Left: Journee with her parents, Ebony and Antwonn, and medical team members (left to right, back to front) Dr. Hilary Gwynn, Colleen Lenz, Dr. Sarah Korth, Dr. Shenandoah Robinson, Dr. Frank Pidcock and Dr. Ranjit Varghese at a follow-up appointment one year after her surgery.



Physical therapist Alissa Marzetti checks in with Journee a year after Journee's surgery.



“What I’ve seen in Journee the most is how these surgeries have added to who she is and her self-esteem.”

– Ebony, Journee’s mom

A Superstar

This past September, Journee started kindergarten. When she entered the building with her bright purple walker, teachers and students gathered around, excited to meet the newcomer with the big smile. When Journee’s peers asked about her walker, she simply said, “It helps me walk. I just walk a little differently.”

Outside of school, Journee does physical therapy and participates in adaptive dance classes, horseback riding, swimming and gymnastics. “That’s four to five hours of therapy a week without her even knowing it,” Ebony says. “It’s what she loves, and she gets to be with her friends.”

Of all the ways in which surgery and therapy have helped Journee, Ebony says it’s Journee’s self-esteem that has benefited the most. “These surgeries, and the love of her parents,” Ebony says, “have added to who she is and her self-esteem.”

Today, Journee uses her walker 85 percent of the time. She’s an active 5-year-old and an inspiration to everyone she meets. Ebony attributes Journee’s success to her daughter’s unwavering desire to break down barriers, and to the amazing teams at Johns Hopkins and Kennedy Krieger.

Ebony and Antwonn always believed their daughter would walk—it’s Journee’s amazing spirit that’s been the surprise. “Journee’s light makes you feel good about yourself. She is a superstar,” Ebony says. “Journee makes you feel empowered, just to see her authentic self, standing tall, purple walker and all.”

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



WHEN VICTORIES ADD UP

For children with AFM, rehabilitation and recovery can be intense. The independence they gain back makes all the difference.

Above: Geuko. Right: Geuko rides a tricycle with physical therapist Dr. Courtney Porter. Far right: Physical therapist Dr. Karli Stager positions Geuko for a sitting balance, with Dr. Stager supporting Geuko's head, and no other bracing being used.

“I can’t hold my head up, and I’m feeling strange,” Geuko told his parents on July 22, 2016.

They took him to an urgent care center near their home in the Netherlands. Doctors thought Geuko might have Guillain-Barre syndrome. They sent him by ambulance to the hospital. On the way, Geuko experienced a sudden attack of pain and paralysis and stopped breathing.

“Seeing your almost 4-year-old in a room, intubated, and you don’t know what happened, and he can’t talk—and he was a talker!—lying there...that’s not what you want,” says Gert Jan, Geuko’s dad.

A few weeks later, Geuko became the first person in the Netherlands to be diagnosed with acute flaccid myelitis, also known as AFM.

A RARE, POLIO-LIKE CONDITION

AFM has likely been around for a long time, but only in the past five years have doctors seen an uptick in diagnosed cases, and more so in even than in odd years. AFM tends to start out with what appears to be a cold, but then develops very quickly into floppy paralysis in one or all limbs, and often an inability to smile, talk or even breathe, explains Dr. Cristina Sadowsky, clinical director of Kennedy Krieger’s International Center for Spinal Cord Injury.

“They’re resilient kids. It’s exciting to see the progress they make.”

– Dr. Courtney Porter, physical therapist



Estimated to affect only one or two in one million people, most of them young children, AFM does not interfere with thinking or sense of feel, explains Janet Dean, nurse practitioner for the center. About 10 to 20 percent of individuals with AFM make an almost full recovery, while others regain only some of the movement they lost. The range of recovery is as varied as the ways in which AFM affects those diagnosed with it. Since 2014, Kennedy Krieger has treated more than 80 children with AFM, “and we learn more about how to treat it with each child we see,” Dean says.

One probable cause of AFM is enterovirus D68. It’s a common virus, usually inflicting no lasting harm, but research suggests it may be causing some people to develop AFM.

After Geuko’s initial illness passed, he was left almost completely paralyzed and on a ventilator. He spent nearly two years at a rehabilitation center in Germany, but what Gert Jan really wanted was to take his son to Kennedy Krieger Institute, which he’d read about online. He’d even gotten in touch with Dr. Sadowsky. In June 2018, Dr. Sadowsky visited Geuko and his family and therapists in the Netherlands.

“Geuko’s family had taken such good care of him, and he’d received good therapy, but what he needed was activity-based rehabilitation therapy,” also known as ABRT, in which Kennedy Krieger excels, Dr. Sadowsky explains.

‘ALL THEIR ATTENTION TO THE KIDS’

Last February, Geuko and Gert Jan made it to Kennedy Krieger. For three months, Geuko did a combined three to five hours of intense physical, occupational and speech-language therapies a day. Fun activities like crafts and coloring helped him regain movement in his hands. Stretching and strengthening had him sitting up on his own again, walking short distances with a walker and transferring himself, with only minimal assistance, from his bed to his wheelchair—all things he hadn’t done in two and a half years.

“He made phenomenal progress while he was here,” says physical therapist Dr. Courtney Porter. “Our big goal was increasing independence, and that’s exactly what he did.”

Respiratory therapists helped start the process of gradually weaning Geuko off the ventilator. Naturally, Geuko had developed anxiety at the very thought of going off of it. But his therapists went slowly, starting with just a few seconds of decreased support to the lungs for breathing, explains pediatric respiratory therapist Craig Engler. By the time Geuko left Kennedy Krieger, he could breathe for 10 minutes at a time on his own.

Geuko keeps up his therapies at home, and amazes his parents every day with his progress. He can now breathe on his own for more than an hour at a time. Gert Jan hopes to bring Geuko back to Kennedy Krieger for additional therapy, and describes all of the doctors, nurses, therapists and other providers at the Institute as Geuko’s angels, “and the head angel is Dr. Sadowsky. ... They give all their attention to the kids.”



WHEN BREATHING MEANS FREEDOM

One day in early October of last year, Ava, then not quite 4, suddenly couldn't move her legs and had trouble breathing. Her local hospital in Maryland sent her to The Johns Hopkins Hospital, where she was put on a ventilator and diagnosed with AFM. Her diaphragm—the muscle that pumps the lungs—was no longer working.



“In 48 hours, I literally went from having a bouncing 4-year-old to wondering if she’s going to make it.”

– Amanda, Ava’s mom

Some children with AFM rely indefinitely on ventilators to help them breathe. But Dr. Sadowsky wondered if a diaphragmatic pacer could reactivate Ava’s diaphragm. The pacers had been used in patients with AFM before, but never to any great effect, and all had been implemented at least six months after paralysis. So Dr. Sadowsky said, “Let’s put this pacer in early, and see if that will help save some diaphragm.”

As soon as the pacer was in, the left side of Ava’s diaphragm started to contract, then expand. Within days, Ava was breathing with decreased support from the ventilator. Her diaphragm had been saved.

But she’d lost her voice, and her ability to move just about every muscle in her body. Four months of intense therapies at Kennedy Krieger’s inpatient rehabilitation hospital helped Ava start to get her life back. Initially, she communicated by fixing her eyes on pictures on a board, explains speech-language pathologist Dana Wanyo. Special tongue and swallowing exercises helped her strengthen her oral and pharyngeal muscles to allow her to swallow safely and speak. Ava speaks with the aid of a Passy-Muir valve, which Wanyo taught her to use to control airflow through her tracheostomy.

Occupational therapist Justine Small helped Ava strengthen her neck muscles to be able to use her head to drive her power wheelchair and use switch-activated toys. “We’re always creatively problem-solving to help our patients become more independent, particularly through play,” Small says.

Physical therapist Kimberly Peterson now visits Ava at home through Kennedy Krieger’s Community Rehabilitation Program. To help Ava increase her core strength, they’ll sit on the floor—Peterson supporting Ava with her hands—while playing games or reading books. And while Peterson moves Ava’s arms and legs through their full range of motion, Ava pretends she’s riding a bicycle or doing “ballerina kicks.” To make therapy more enjoyable for Ava, Peterson lets her choose many of the activities they do together.

Now that Ava can talk again, she uses voice-activated technology to do things like turn the lights on and off. “That expands her independence in her home environment,” explains speech-language pathologist Demetria Padussis, who also provides home therapy to Ava through the Community Rehabilitation Program.

And thanks to the pacer, Ava can now breathe with decreased ventilator support for a couple of hours at a time. “At some point, we hope she can be off the ventilator during the day,” Dr. Sadowsky says, “because without the vent—that’s freedom.”



Top left: Ava. Left: Ava works with physical therapist Kimberly Peterson. Right: Ryleigh. Top right: Ryleigh works with occupational therapist Frances Paradise and rehabilitation technician Shawn Reichenberg Jr.

A STRATEGY FOR EACH CHILD

Two weeks before Ava developed AFM, Ryleigh, now 4, came down with a cold and then, four days later, with paralysis. She did inpatient and outpatient therapy in Virginia, where her family was living at the time, and started intensive inpatient therapy at Kennedy Krieger in June.

She made excellent gains in using her legs and left arm, “but we weren’t seeing any significant improvements in her right arm,” says Dr. Michelle Melicosta, medical director of the Institute’s inpatient rehabilitation hospital.

Dr. Melicosta and her colleagues suspected Ryleigh might benefit from nerve transfer surgery, in which segments of healthy nerves are transferred to the nerves that aren’t working, to reinvigorate them. The surgery took place at Johns Hopkins on July 15, and it’s hoped that Ryleigh will start to get more motion back in her right arm by early next year.

Because AFM can change a child’s life so abruptly, and the therapies that children with AFM do are so intense, pediatric psychologists usually step in to help children understand and cope with what’s happening. “Distress and anxiety are common in this population,” says pediatric psychologist Dr. Margaret Tunney. “It’s to be expected. Their ability to move their body has changed very quickly, and they are doing a lot of very difficult tasks.”

Dr. Tunney and her colleagues develop individual strategies for each child to help them participate in therapies and meet their goals. They often join physical, occupational and speech-language therapy sessions to implement child-friendly strategies to maximize rehabilitation potential. Dr. Tunney worked closely with Ryleigh’s therapists and mom, Mallory, to learn more about Ryleigh and develop an individualized program for her therapy sessions.

During her eight-week inpatient admission, Ryleigh increased the distance she could walk with a walker from 150 to 300 feet—the length of a football field. This past fall, she started outpatient therapy three days a week at Kennedy Krieger, still following the special program Dr. Tunney created for her.

“She’s doing amazing!” Mallory says. “The amount of confidence she’s gained since going to Kennedy Krieger has been out of this

“The amount of confidence she’s gained since going to Kennedy Krieger has been out of this world! That’s made all the difference in her gaining back some of her independence.”

– Mallory, Ryleigh’s mom



world!” Instead of doubting herself and her abilities, Ryleigh now trusts herself in what she can do. “That’s made all the difference in her gaining back some of her independence.”

It’s successes like these that give children with AFM and their families hope and a reason to stick to their therapies. As the victories add up—two steps becoming four, five minutes off the ventilator becoming an hour, tiny head or toe movements activating a wheelchair—a new vision of independence starts to come into focus. And that’s the ultimate reward for all of their hard work. – *LT*

Visit [KennedyKrieger.org/AFM](https://www.kennedykrieger.org/AFM) to learn more about AFM, and visit [KennedyKrieger.org/Geuko](https://www.kennedykrieger.org/Geuko) to watch a video about Geuko.



Thriving Through Joyful PLAY

AT PACT, SPECIALIZED MEDICAL CARE AND INCLUSIVE LEARNING EXPERIENCES POSITIVELY IMPACT CHILDREN AND THEIR FAMILIES FOR YEARS TO COME.



Right: World of Care infant room teachers Anita Marine (left) and Kelly Rayner with children at PACT's World of Care.

As Thailya looks up at the colorful fabric waving above her head, a smile spreads across her face.

“Can you catch the rainbow?” asks Sharon Holloway, PhD, director of the World of Care medical child care program that Thailya, 2, attends.

Thailya and her classmates love “parachute time,” when they gather on the playground under the billowing, multi-colored fabric. It’s an activity that children of all abilities and neurological conditions can enjoy.

“This is their world,” says Centura Lewis, a child care teacher at World of Care. The playground, designed to accommodate all levels of mobility and cognitive ability, is where children attending World of Care enjoy fresh air and sunshine, weather permitting, between indoor activities. On the playground, children blow bubbles, paint pictures, play with trucks, maybe pass a ball back and forth with a friend—typical kid stuff, adapted to suit their abilities.

“We focus on the joy of play, which promotes children’s health and development, and on the joy of being included in all ways,” Holloway says. “If we’re doing a mural outside, we’ll tape a paper to the wall, and let the kids slather it however they want, helping them in any way they need. Everyone can participate; this is their home away from home.”

Supporting Children and Families

Located just outside of Baltimore, World of Care offers full-day care for children, up to age 5, with complex medical conditions—such as chronic lung disease, asthma, brain injuries and cerebral palsy—requiring nursing interventions throughout the day. Staff members include experienced child care teachers, nurses, social workers, service coordinators, and physical, occupational and speech-language therapists. It is the only medical child care program in the Baltimore area.

World of Care is run by PACT: Helping Children with Special Needs. Founded in 1981, PACT has been affiliated with Kennedy Krieger Institute since 1998. A nonprofit organization, it promotes the development of young children with special needs, and their families, through specialized child care, early intervention services, family support services, parent education, counseling and professional training.

“PACT provides critically important services that are integral to Kennedy Krieger’s mission of transforming children’s lives,” says Dr. Bradley L. Schlaggar, the Institute’s president and CEO. “The children that attend its programs receive the medical care and enriching experiences they need to get the best possible start in life.”

“The first five years of life are so essential—that’s when the greatest learning takes place,” adds Audrey Leviton, LCSW-C, PACT’s executive director. “At PACT, we’re committed to reaching children during that time by providing high-quality programs that will impact them for the rest of their lives.”





“PACT provides safe, nurturing, high-quality child care programs for families who have nowhere else to turn.”

— PACT Executive Director Audrey Leviton

PACT also runs a program called the Therapeutic Nursery, for children and their families experiencing homelessness in Baltimore. Situated inside the largest family homeless shelter in the city, the Therapeutic Nursery offers attachment-based, trauma-informed child care for children under age 3. It also offers the only Early Head Start program in the city specifically for children experiencing homelessness. The U.S. Department of Health and Human Services has named the Therapeutic Nursery a national model for working with children and families who are without permanent housing.

“You can imagine how stressful being homeless is for any parent, let alone parents with very young children,” explains Kim Cosgrove, the Therapeutic Nursery’s director. “Our goal is to support parents during this difficult time so they can nurture their baby and be the best parents they can be.”

One of the ways in which the Therapeutic Nursery accomplishes this is by hosting mindful awareness parent-child play sessions. “We invite each parent to be the curious observer of their child’s curious exploration, and to follow their child’s lead in play. The moment-to-moment interactions that take place strengthen the parent-child relationship,” Cosgrove says. “Through secure attachment with a caregiver, a child learns two critical things: identity and emotional regulation—essential building blocks for a child’s social-emotional development, school success, and emotional and physical health.”

Other services offered by the Therapeutic Nursery include family support and assistance in accessing medical and other community resources, and physical, occupational and speech-language therapies for children, as needed.

Far-Reaching Impact

Through ongoing staff training and continuous interactions with other medical child care providers, PACT’s staff members stay up to date on the latest techniques for helping children with complex needs. And they share what they learn—both with their peers and with various city, state and national legislative bodies—to advocate for families facing challenges related to homelessness, complex medical needs, and developmental and intellectual disabilities. Therapeutic Nursery staff members have authored more than six journal articles and a guidebook on interventions developed and practiced at the nursery.

PACT also offers unique learning experiences to interns and trainees, who spread PACT’s methods to medical and therapeutic programs across the country. And through regional training sessions and presentations at national and international conferences, PACT has trained more than 7,000 professionals in its early intervention strategies.

PACT is able to reach so many fellow professionals—and through them, so many children and families—because its staff members are fully committed to the work they do. They know the importance of the early interventions they provide. “We want the children to reach their fullest potential,” Lewis says.

“I love being able to make a difference for the children,” World of Care teacher Ikeia Alexander adds. “I want to see all of them thrive.”
— *LT*

Visit KennedyKrieger.org/PACTVideo to watch a video about PACT, and visit KennedyKrieger.org/WOCSam to read about Sam, an alum of—and former intern with—World of Care.

To help PACT provide medical child care to more children, please consider donating to the Mark and Sandy Furst Scholarship Fund. The Rosedale Federal Savings & Loan Association will match all donations to the fund, up to \$100,000. Visit KennedyKrieger.org/FurstFund to learn more.



Thailya reaches up toward the rainbow parachute.



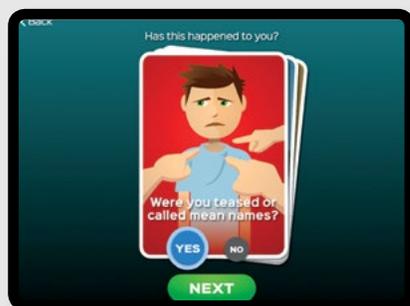
Identifying Trauma in Children With Autism

Children with autism often find it difficult to describe traumatic experiences. This new app will help.



A new tablet-based app developed by Dr. Daniel Hoover, a clinical child and adolescent psychologist at Kennedy Krieger Institute's Center for Child and Family Traumatic Stress, allows clinicians to better assess children with autism spectrum disorder (ASD) or intellectual disabilities for trauma.

"We've found that children on the autism spectrum often have difficulty talking about any traumatic experiences they might have had," Dr. Hoover says. "Research shows they tend to minimize or deny their experiences and feelings. And when given a paper-and-pencil questionnaire, they often don't understand the questions or don't fill them out completely."



Screenshots from the app.

"There's an increasing role in using apps and touch-screen devices in teaching children with autism, and many children with autism use apps to learn and communicate," Dr. Hoover explains. "This app is a natural extension of that."

But this new app's touch-screen interface, multi-modal presentation, and cartoon figures and graphics make it easier for children with limited communication abilities to report their experiences. The app asks questions about potentially traumatic events and symptoms, and offers clear response options like "always," "sometimes" and "never." Children may read the questions themselves, or choose to have the app read the questions aloud. With one question per screen and a "next" button being the only way to proceed, questions cannot be skipped.

Children with ASD are more likely to be bullied than children without disabilities, and repeated bullying can produce trauma. Other potentially traumatic experiences include neglect and witnessing violence. Symptoms of trauma can include losing sleep or having flashbacks or anxiety about the experience.

Because children with ASD often have difficulty answering questions, many clinicians rely on parent or teacher reports to determine if a child is experiencing trauma. "But research shows that adult reports miss a lot of the experiences and symptoms," Dr. Hoover says. "This app allows children who have autism and have been traumatized to self-report on those experiences."

For the app's pilot test, Dr. Hoover worked with former Kennedy Krieger postdoctoral fellow Dr. Elizabeth M. G. Romero, now a clinical psychologist in Massachusetts. Last January, they published a study in the *Journal of Autism and Developmental Disorders* demonstrating the app's validity and reliability for children ages 6 to 14, the app's target age range. Verizon Wireless provided funding for the app's initial programming.

Called the Interactive Trauma Scale, the app is now being used at Kennedy Krieger's Center for Child and Family Traumatic Stress. After further testing and fine-tuning, Dr. Hoover hopes to make it available to clinicians around the world.

"We hope the app will not only help children who've experienced trauma, but also help us better differentiate between ASD-related behaviors and trauma symptoms," Dr. Hoover says. "With that information, we'll be able to improve treatment and care." — *LT*

Visit KennedyKrieger.org/TraumaticStressCenter to learn more about the Institute's Center for Child and Family Traumatic Stress.

"This app allows children who have autism and have been traumatized to self-report on those experiences."

— Dr. Daniel Hoover



WE ARE
ONE
KENNEDY KRIEGER

Inaugural Employee Giving Campaign Supports the Families of Kennedy Krieger

Kennedy Krieger Institute's inaugural "We Are One" employee giving campaign this past fall was a huge success! Forming a united front, Institute employees raised \$84,889.27 to support patients and students receiving services at Kennedy Krieger.

All donations went to the Mary Snyder-Vogel Family Fund, a resource for any student or patient family needing assistance with paying for medical or therapeutic services or equipment not covered by insurance. The fund also makes one-time grants to cover basic and incidental needs.

The "We Are One" campaign exemplifies the exceptional passion and commitment that Kennedy Krieger employees have for the Institute's mission of improving the lives of children and young adults with disorders of the brain, spinal cord and musculoskeletal system.

Baltimore Running Festival

Team Kennedy Krieger rolled out all the stops at this year's festival.

On October 19, 173 racers sporting green Team Kennedy Krieger T-shirts made their way through the streets of Baltimore, representing Kennedy Krieger Institute's International Center for Spinal Cord Injury at this year's Baltimore Running Festival.

Teammates participated at all accessibility levels, including handcycling for those experiencing paralysis of the lower body. Together, they raised more than \$100,000 to support Kennedy Krieger's rehabilitation programs and the Institute's activity-based, innovative therapies, which bring "Hope Through Motion" to patients and their families.

Over the past eight years, Team Kennedy Krieger has raised nearly one million dollars through participation in the festival. The team's goal is to increase the number of Kennedy Krieger patients able to participate in the race, and to open the door to improved physical fitness for those with disabilities.

The Institute would like to thank the team members and their supporters—including title sponsors Erickson Living and Restorative Therapies—for making a difference in so many patients' lives.



SAVE THE DATES!



ROAR for Kids

Saturday, April 25, 2020

Oregon Ridge Park

13401 Beaver Dam Road

Cockeysville, MD 21030

Join us for Kennedy Krieger Institute's ROAR for Kids, a 5K run, low-mileage walk and jungle-themed family festival. All proceeds from the event will support research and programs to help kids at Kennedy Krieger. Visit KennedyKrieger.org/ROAR for more information.



Hats & Horses

Friday, May 1, 2020

The Winslow Room at the

Parker Metal Building

333 West Ostend Street

Baltimore, MD, 21230

New location!

Join the Women's Initiative Network for Kennedy Krieger Institute at its fifth annual Derby-style fundraising event. Visit KennedyKrieger.org/HatsAndHorses for more information, and email Allyson Peters at PetersA@KennedyKrieger.org to be added to the invitation list or to become a sponsor.

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





Kennedy Krieger Institute

707 North Broadway
Baltimore, Maryland 21205

NON-PROFIT
U.S. POSTAGE
PAID
PERMIT #7157
BALTIMORE MD



Your support helps amazing patients like Geuko.

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

Visit KennedyKrieger.org/YE19 to make your donation today!

Geuko, pictured here with Dr. Cristina Sadowsky, traveled to Kennedy Krieger from the Netherlands for treatment for AFM. Read his story on page 8.

WHY WE GIVE

"We give to Kennedy Krieger because we know it'll really make a difference in children's lives."

– Dr. Ron and Barbara Walcher, donors

Dr. Ron Walcher, a former doctor at Kennedy Krieger, and his wife, Barbara, are members of the Kennedy Krieger Society. Visit KennedyKrieger.org/Walchers to read their story.

