

potential

A publication of Kennedy Krieger Institute Fall | Winter 2018

Go, Landon!

Determined Athlete, Dedicated Donor

Culinary Quest

Recipe for Inspiration

Lydia Smiles Again

Teamwork + Imagination

Center Stage

Patient to Pageant



Kennedy Krieger Institute



Greetings from our **New CEO!**

Hello, all,

I'm proud to have joined Kennedy Krieger as its president and CEO. As a pediatric neurologist, physician and researcher, I've admired the Institute's work and reputation for many years. As a parent, I appreciate the interdisciplinary, patient-centered approach everyone here takes to ensuring patients receive the very best care.

That's why I'm so excited to share with you the stories in this issue of *Potential*!

You'll read about Landon, who competes in our adaptive sports program, and about Kailyn, who first came to Kennedy Krieger struggling to walk and talk. Kailyn's now an ardent spokesperson for individuals with disabilities.

Jeremiah has autism and just graduated from our high school. His story is near and dear to my heart, because my mom was a special educator for Chicago's public schools. Jeremiah's taking the culinary world by storm, proving that individuals with neurodiverse traits can fulfill their dreams and inspire others.

And how could you not be captivated by Lydia's smile? Lydia sustained a traumatic brain injury last fall, but she's working hard to regain mobility and never accepts the word "can't."

These kids and their families are the reason all of us at Kennedy Krieger come to work each day. We're honored to help them embrace life and defy limits, and we're grateful for the role you play in making it all possible. Enjoy the stories!

Bradley L. Schlaggar, MD, PhD
President and CEO

P.S. I welcome your comments, questions and suggestions—email me at: CEO@KennedyKrieger.org

On the cover: Landon, 8, trains with Kennedy Krieger's adaptive sports team, the Bennett Blazers. He also fundraises for the Institute.

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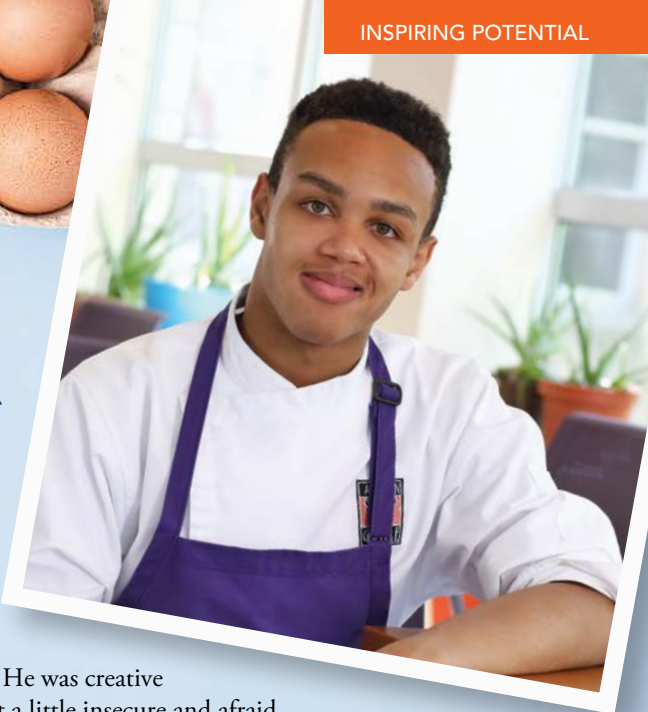
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for more inspiring stories, news and updates.

Ingredients FOR Inspiration

Jeremiah, who has autism, trains with chefs around the country, and encourages others to follow their dreams.

By Christianna McCausland



Jeremiah's going places—literally. An aspiring pastry chef and recent graduate of Kennedy Krieger High School, Jeremiah, 19, has traveled to New York, New Orleans and Washington, D.C., to cook with some of the best chefs in the country.

He's also modeled for Tommy Hilfiger's adaptive clothing line, and authored—with his mom, Simone—"Here's What I Want You To Know," a book about autism. Last year, Jeremiah was a youth ambassador for Kennedy Krieger Institute's Festival of Trees. Dedicated to both cooking and disability awareness and advocacy, Jeremiah is living a life full of promise and exciting opportunities. But it wasn't always this way.

Jeremiah, who lives in Maryland, was diagnosed with autism at Kennedy Krieger when he was in third grade. His local school system, Simone says, wasn't equipped to follow his individualized education program, and he was often bullied. In middle school, Jeremiah enrolled in Kennedy Krieger's Fairmount school campus in downtown Baltimore.

"At Kennedy Krieger, I saw diversity and a structured education," Simone says. "I knew my son would have a team of people solely responsible for charting his academic progress.

He was more than capable of doing his school work. He just needed the right environment."

Jeremiah's engaging personality impressed his Kennedy Krieger teachers

from the start. He was creative and caring, but a little insecure and afraid to make mistakes, remembers Deidre Rabuck, the Fairmount school campus's assistant principal.

"It was clear he hadn't had an academic experience where he felt good about himself," Rabuck says. "But once he knew it was okay to be himself, he blossomed."

Jeremiah started learning to cook from his maternal grandmother when he was 13. In middle school, he made books in which he'd group activities and words around foods, as a chef might organize a kitchen around ingredients and recipes. At Kennedy Krieger High School, Jeremiah worked at the school's student-staffed, teacher-led Cafe James.

To encourage her son's interest in cooking, Simone started the YouTube channel "Jeremiah's Cooking Adventures," where she and Jeremiah post videos of Jeremiah learning to cook. He also has a website with the same name. Jeremiah and his mom reach out to famous chefs like "Top Chef" contenders Kwame Onwuachi and Chris Scott, who've invited Jeremiah to cook with them. More apprenticeships are in the planning stages.

This past spring, Jeremiah returned to Kennedy Krieger's Fairmount Campus to give a speech at the school's graduation. He encouraged the students not to let their disabilities hold them back.

For everyone listening to his speech, "Jeremiah represented hope, because he's determined to not let having autism get in the way of his dream of becoming a pastry chef," Rabuck says. "He wanted to learn—he just needed the opportunity."

Visit KennedyKrieger.org/Schools to learn more about Kennedy Krieger's school programs. Visit KennedyKrieger.org/Jeremiah for Jeremiah's cheesecake recipe.

Far left: Jeremiah was a Festival of Trees 2017 youth ambassador (pictured with Lainy LeBow-Sachs). Left: Jeremiah prepares a cheesecake at Cafe James. Above: Jeremiah co-wrote a children's book about autism.



Smiling Again

Specialists from across Kennedy Krieger's continuum of care are working together to help Lydia recover—and get her smile back—following a traumatic brain injury.

Dale will never forget the day he saw his daughter Lydia walk again. It was back in January, and Lydia, now 11, had been at Kennedy Krieger Institute's inpatient rehabilitation hospital for about two months. She'd experienced a traumatic brain injury the previous fall, when a truck hit her family's minivan on their way home from church, and she was relearning how to do just about everything.

"One of her therapists said, 'Show your dad what you can do!'" Giddy with excitement, Lydia walked part-way across the room, all by herself. "It was a big moment," Dale says.

That's because when Lydia arrived at Kennedy Krieger, she couldn't sit up, or even hold her head up on her own. Her injury had disrupted the signaling process her brain uses to get her body to move. She could give a thumbs-up for "yes" and a thumbs-down for "no," and she could say "mommy." But her parents had no idea if she'd ever talk in complete sentences again, let alone laugh, tell a joke or even smile.

Nevertheless, Lydia started right away on the road to recovery with a combined three to four hours of intensive physical, occupational and speech-language therapies a day, much of it disguised as games or other fun activities. She also began working with specialists in neuropsychology, behavioral psychology, child life, therapeutic recreation and education.



Above: Lydia and her parents, Dale and Amy.



As Lydia's injury was to the right side of her brain, which controls left-side vision and movement, she didn't initially respond to any stimuli on the left side of her body. Many of her therapies were geared toward getting her to use her left side again. For example, physical therapist Elena Bradley used musical toys to get Lydia to look to the left, and occupational therapist Danielle Matteo encouraged Lydia to color on the left side of a piece of paper.

Other therapies helped Lydia redevelop her cognitive abilities and memory. For example, speech-language pathologist Dana Wanyo helped Lydia create a memory log of pictures and words indicating what had happened throughout the day.

Bradley also worked Lydia through a range of supported sitting and standing positions to get her used to being upright again. And Lydia strengthened her arms, legs and core at aquatic therapy sessions.

"Her therapists kept pushing her in a good way," says her mom, Amy. Lydia started telling jokes again. Soon, she was ready to try walking—first with a walker, then a cane. And then, as Dale looked on, Lydia walked without any assistance at all.

'Aha!' Moments

By the end of January, Lydia was home from the hospital and attending the Institute's Specialized Transition Program, an intensive outpatient program, where she continued to make great progress. "This program was designed for children like Lydia," explains Dr. Beth Slomine, co-director of the Institute's Center for Brain Injury Recovery. "She made so much progress as an inpatient, and we wanted to maintain that momentum through daily therapies in an intensive outpatient setting."

Lydia more than kept up the pace. "She surprised herself—and us—every day with the gains she was making," physical therapist Erin Naber says. "She'd come in, and all of a sudden, she could move her left foot or open her left hand—something she couldn't do the day before. We had a lot of 'Aha!' moments."



Above: In outpatient therapy, Lydia practices reaching with her left arm with occupational therapist Stacy Merenstein. Lydia's right arm is in a removable cast to encourage left-arm movement.

Left: A therapy ball helps Lydia develop strength and movement in her left arm.



Left: Making cookies with speech-language pathologist Laura Hyde, Lydia practices following directions and narrating what she's doing.

Below: Lydia organizes picture cards into their correct sequence, then tells a story based on the cards.



Therapists at the program helped Lydia become more independent and get ready to go back to school. Lydia did craft projects with occupational therapist Nicole Whiston, using markers, glue sticks and scissors to improve her fine motor skills. "She was so motivated by imaginative, fun activities that it was easy to keep her engaged," Whiston says.

In the intensive outpatient program's classroom, Lydia started doing schoolwork again. "We figured out where she was in reading, writing and math," explains educational specialist Julie Gardner, "and built a program for her." Gardner ensured that Lydia had an individualized education program (IEP) in place before returning to school.

A Joke and a Smile

After attending the intensive outpatient program, Lydia started weekly physical, occupational and speech-language therapy sessions at the Institute's outpatient clinic in Columbia, Maryland, near where she lives. She also had a follow-up evaluation at the Institute with a physician, a neuropsychologist, a behavioral psychologist and Gardner. She'll continue to be evaluated by her follow-up team once or twice a year for at least a few years.

Near the end of the school year last spring, Lydia returned to school. "She's very social," Amy explains. "I know she would have been devastated if she hadn't gotten to finish up the school year."

On her first day back, "she was so glad to see everyone. She knew the names of all her teachers and classmates," Amy says, "and she had a joke—and a smile—for everyone." — *LT*

Visit [KennedyKrieger.org/BrainInjuryCenter](https://www.kennedykrieger.org/BrainInjuryCenter) to learn about the Institute's Center for Brain Injury Recovery. Visit [KennedyKrieger.org/Lydia](https://www.kennedykrieger.org/Lydia) for a video and a more in-depth story about Lydia.

TAKING Center Stage

Kailyn, who experienced a brain injury at birth, uses her pageant platform to advocate for children with disabilities.

As Kailyn stepped up to the registration table, she exuded a sense of confidence and ease that her mother, Kimberly, never would have thought possible when Kailyn was younger.

Kailyn had been born about four months early, experiencing a brain injury at birth. As a baby and toddler, she was nonverbal and extremely hyperactive, wouldn't respond to her name, and had difficulty walking due to low muscle tone, called hypotonia, especially on her left side, Kimberly explains.

But on July 3, Kailyn, then 9½ and wearing her pink-and-white "Little Miss Delaware" sash, officially entered the 2018 Little Miss United States competition. A few days later, she donned a red satin ball gown—with hoop skirt and crinoline petticoat—and a pair of low-heeled sparkly pumps with ankle straps, and glided down the pageant catwalk.

When a panel of judges asked Kailyn about her platform as Little Miss Delaware, she wasn't nervous. She'd come so far from her earliest days at Kennedy Krieger Institute, when she still used gestures and mimicry to communicate with others, and she'd practiced what she was going to say.

"You cannot hold kids with disabilities back," Kailyn told the judges. "You have to expect that they can do anything!"

Kailyn's perseverance led her to become Little Miss Delaware 2018. She wants to be an actress, a dancer, a pianist and a gymnast when she grows up.

(Pageant photograph by Barry Freeman.)

Early Therapies Paved the Way

Kailyn was not quite 3 when she first started coming to Kennedy Krieger. She began with speech-language therapy, and was soon doing occupational and feeding therapies, too.

Hypotonia made it hard for her to move her mouth and facial muscles to speak and eat, and to keep her balance when she walked.

She soon received a variety of diagnoses: mixed receptive and expressive language disorder, which made it difficult for her to express herself and understand what others were saying; dysarthria, a speech disorder caused by the muscle weakness of hypotonia; dyslexia; and other disorders.

But six-plus years of therapies have helped Kailyn become who she is today: a fourth-grader who excels at spelling and multiplication; a dancer, pianist and gymnast; a social member of her church and community; and a pageant winner with an important message to share.

"Kailyn's therapists at Kennedy Krieger have gotten her from probably needing special education and heavy medical intervention for the rest of her life," Kimberly says, "to being at a place where she can function almost normally. That comes from her going to Kennedy Krieger for so long."

Kailyn's occupational therapists have helped her develop her fine motor skills, use the left side of her body more easily, and organize and develop her thoughts. Her most recent occupational therapist, Emily Ammann, helped her with both writing and organizational skills.

Ammann found that while creative ideas came easily to Kailyn, it was hard for



her to organize them into coherent sentences, and that was getting in the way of the mechanical process of writing. So Ammann helped Kailyn organize her thoughts with graphic organizers like flow charts and story boards.

Because Kailyn loves movement and dancing so much, Ammann worked breaks incorporating these types of activities into Kailyn's therapy exercises. "She's so driven to move, and to dance, so it became a motivation during therapy," Ammann explains.

After her therapy appointments, Kailyn often visits one of the Institute's playrooms staffed by child life specialists. When she was younger, she wouldn't engage with the other children in the playroom, says child life specialist Sherri Williams. But that's changed now—Kailyn loves meeting up with her friends in the playroom and engaging in imaginative play with Williams.

"I had to convince Kailyn just this past year," Kimberly says with a smile, "that Kennedy Krieger is a clinic, not a playground."

Last June, Kailyn was diagnosed with attention deficit hyperactivity disorder (ADHD)—a diagnosis Kimberly long suspected—following a day-long neuropsychology evaluation at Kennedy Krieger.

"We were so impressed at how far Kailyn has come," psychologist Dr. Shelley McDermott says, "given her complicated medical history, particularly her history of very premature birth." As part of Kailyn's continuing interdisciplinary care plan, Dr. McDermott recommended that Kailyn and her mother participate in behavioral therapy to learn strategies for managing ADHD symptoms.

From Patient to Pageant

In addition to her therapies, Kailyn also takes piano lessons and ballet, hip-hop, jazz and gymnastics classes. When asked by a pageant judge what she wanted to be when she grew up, she replied, "I want to be an actress, a dancer, a pianist and a gymnast, because I like them all, and those are my dreams."

"You cannot hold kids with disabilities back. You have to expect that they can do anything!"

– Kailyn, 10



Above left: Kailyn loves playing at Kennedy Krieger's Fairmount Campus playground.

Left: Kailyn works on her writing skills at Kennedy Krieger.

Below right: Kailyn and her mom, Kimberly.

Below left: Kailyn works with Kennedy Krieger psychologist Dr. Shelley McDermott.



When Kailyn didn't make it into her studio's dance company last year, she was offered a scholarship to participate in the Miss United States Pageant organization's Little Miss Regional Pageant for Delaware, Maryland and Washington, D.C., instead. A pageant representative had been at the company auditions, and had noticed how much Kailyn loved dancing. At the regional and national pageants, Kailyn joined her fellow contestants in group dance performances.

Since winning the Little Miss Delaware crown, "Kailyn hasn't stopped smiling," Kimberly says. She particularly enjoys the public appearances she makes as a crown holder—playing the piano at nursing homes, for example, and meeting with elected government representatives to advocate for the inclusion of children with disabilities in the community.

One energetic step at a time, Kailyn's demonstrating that kids with disabilities can achieve amazing things—they just need to be given the chance. – *LT*

Visit **KennedyKrieger.org/OutpatientPrograms** to learn more about the Institute's many outpatient programs and clinics.



PURE Motivation

Landon's not only a decorated athlete—he's also one of Kennedy Krieger's most dedicated fundraisers.

Landon has never let his physical disabilities slow him down. Even when he was 15 months old and unable to walk because his left arm and leg were stiff and weak from left-sided hemiparesis, a form of cerebral palsy, he still kept trying to keep up with his older brother.

But over the past seven years, as Landon's participated in various therapies and programs at Kennedy Krieger Institute, his left side has become stronger and more flexible, and coordination between his right and left arms and legs has improved tremendously. He's conquered all kinds of challenges, from the jungle gym to the pitcher's mound, becoming a multi-sport athlete along the way. What's remained constant is his determination to keep pushing himself, every day, to improve his physical abilities and be the best athlete he possibly can.

"He's such a sweet, social kid, and very motivated by sports," explains Dr. Katlyn Billups, one of Landon's physical therapists.

"And he's a natural-born athlete," says his mom, Tania. "The competition, the camaraderie—that's really important to him."

"We really attribute where Landon is now to all the services he's received at Kennedy Krieger over the years."

— Tania, Landon's mom



L

andon, now 8, plays baseball, basketball and soccer on teams with kids without disabilities. The soccer team is a traveling one, and he's received two all-star awards in baseball. He also swims, runs track, plays soccer and basketball, and ascends rock-climbing walls with the Bennett Blazers, Kennedy Krieger's adaptive sports team. Last June, Landon participated in his first track meet, taking home the "Outstanding Male Athlete" trophy at a qualifying meet for Adaptive Sports USA's Junior Nationals.

And for the past two years in a row, Landon, who lives outside of Baltimore, has raised more money for Kennedy Krieger through the Institute's annual ROAR for Kids fundraising event than any other participant under the age of 18. To date, he's raised more than \$5,300 for Kennedy Krieger, and he won first place in the adaptive category for the timed 5K at ROAR 2018, running the race in only 34 minutes—an amazing feat for a child who once struggled to walk.

Early Intervention

A brain scan taken shortly after Landon turned 1 indicated he'd probably had a stroke—which can lead to cerebral palsy—around the time he was born. Landon's pediatricians recommended that his parents take him to Kennedy Krieger.

"Landon's benefited from everyone he's seen at the Institute," Tania says, from occupational and physical therapists to doctors specializing in rehabilitation medicine and orthopedic surgery, and especially his Bennett Blazers coaches. "We feel Landon would not be who he is today without them."

Landon's first taste of intense therapy took place shortly before he turned 3, when he participated in the Institute's constraint-induced therapy program, one of the first clinically-based programs of its kind in the country, explains Dr. Frank Pidcock, the Institute's vice president of rehabilitation.

For six weeks, during daily therapy sessions, Landon would wear a long splint—from fingertips to upper arm—to immobilize his stronger, right arm, encouraging him to use his left arm instead. Under his therapists' direction, he honed the skilled movements he needed to be able to do with his left arm in order to do things like get dressed and buckle his seat belt, explains occupational therapist Teresa Garcia Reidy, of the Institute's Constraint-Induced and Bimanual Therapy Program.

Landon worked hard to master the tasks his therapists assigned him, and ended up meeting all his therapy goals. It was just the beginning of a pattern that's persisted to this day.

During the summers that Landon was 4 and 5, he participated in the Institute's bimanual therapy program, which focuses on coordinating the use of both hands for children with weakness on one side. His parents wanted to be sure he'd be ready for kindergarten—and able to play on the playground equipment like the other kids.

Climbing ladders was difficult for Landon back then, which made jungle gyms almost impossible for him to enjoy. But physical therapist Patricia Turlington worked closely with Landon on his balance, coordination and grip—first holding her left hand over his as he gripped the rungs of a ladder, and gradually, over several weeks, reducing the amount of assistance she gave to his left hand—until he could climb the ladder of a jungle gym on his own.

"Seeing him climb that ladder and get to the top," Tania says, "and seeing the look of accomplishment on his face is something I'll never forget." >>



Far left: Landon has won the Kennedy Krieger ROAR for Kids youth fundraising award for the past two years.

Left: Constraint-induced therapy helped strengthen Landon's left hand and arm when he was 2.

Above right: Landon ascends a rock-climbing wall with the Bennett Blazers.

“Teach kids with disabilities that they can, before they are told they cannot.”

– Bennett Blazers’ motto



Play Ball!

When Landon was 3, his parents enrolled him in the Bennett Blazers’ adaptive sports program. He started out in the program’s weekly motor development class, which focuses on basic sports skills—throwing, catching, climbing, doing obstacle courses—that help kids develop strength, power, coordination, flexibility, balance and agility. As his skills improved, his confidence grew, Blazers coaches Gerry and Gwena Herman say.

Initially, Landon was a little fearful of trying new things. Climbing anything higher than three feet frightened him, as did swimming. But his determination—and the Hermans’ encouragement—was greater than his fear. He’s now competing in swim meets with other athletes with disabilities, and he’s conquered every climbing apparatus at the Kennedy Krieger gym where the Blazers practice.

Landon now trains with the Blazers multiple times a week, swimming year-round and playing other sports seasonally. He’s more skilled in sports than many kids his age are, say the Hermans, who’ve been coaching the Blazers for nearly 30 years. They encourage Landon and his teammates to be well-rounded athletes, holding off on specializing in a single sport until college.

Because Landon was doing intense therapy early on, “he was able to graduate out of it and replace it with sports,” Reidy says. “If possible, we don’t want kids to have to keep coming to therapy every week—ultimately, we want them out doing activities with their peers.”

Landon’s brother, Mason, 11, and sister, Kendall, 6, are also into sports, which means Landon is doing exactly the same types of activities his siblings and friends are doing, all thanks to early interdisciplinary interventions, from therapy to sports.

“We really attribute where Landon is now to all the services he’s received at Kennedy Krieger over the years,” Tania says. Landon’s positive attitude, motivation and determination to always do his best will take him far. – *LT*

Visit KennedyKrieger.org/BennettBlazers for more information on the Bennett Blazers. Visit KennedyKrieger.org/ConstraintBimanual to learn more about the Institute’s Constraint-Induced and Bimanual Therapy Program. Visit KennedyKrieger.org/Landon to watch a video about Landon. Visit HelpKids.KennedyKrieger.org to learn more about giving to the Institute.



Above left: Landon, 8, has been working with the Institute’s Bennett Blazers since he was 3.

Above right: Obstacle courses help Landon improve his agility on the soccer field. Landon often wears braces to stabilize his feet and ankles, and to keep his left leg limber and relaxed.

Above: Landon with Gerry and Gwena Herman, who coach the Institute’s Bennett Blazers.

Measuring the Brain

A new study finds the brains of young children with ADHD differ from those of their peers.

By Elise Welker



Dr. Mark Mahone.

For children with the challenging symptoms of attention deficit hyperactivity disorder (ADHD)—the most commonly diagnosed mental health condition in young children—new research from Kennedy Krieger Institute reveals a likely biological connection: significantly reduced brain size at a young age.

Using high-resolution brain imaging scans along with cognitive and behavioral measures, researchers studied the brain development of 90 preschoolers. It was the first study to identify preschool-age children with ADHD symptoms, and to investigate the brain mechanisms associated with the onset of those symptoms.

One publication resulting from the study shows that 4- and 5-year-olds with ADHD have significantly reduced brain volume across multiple regions of the cerebral cortex, particularly in regions critical to cognitive and behavioral control. A second publication shows similar brain volume reductions among preschoolers with ADHD in



Brain MRI scan taken during the Kennedy Krieger study of preschool-aged children with symptoms of ADHD.

deeper subcortical regions of the brain, including regions known to support attention and motor control.

“ADHD is a biological condition with pronounced physical and cognitive effects,” affecting attention and associated with hyperactivity and impulsivity,

explains Dr. Mark Mahone, senior author of the studies and director of Kennedy Krieger’s Neuropsychology Department.

Study participant Brooke exhibited unusual, often impetuous, behaviors from an early age. “She was constantly moving, even as a baby,” says her mom, Pamela, who recalls taking extreme precautions near roadways, as Brooke would take off running in an instant.

When Brooke was 4, shortly after she was diagnosed with ADHD, she joined Dr. Mahone’s study and began taking medication that would dramatically improve her life. “We needed help before she entered school, so her education wouldn’t be compromised,” Pamela says. “I just wanted her to live the healthiest life possible.”

Today, Brooke, now 14, is doing just that. She recently entered high school with impressive grades, and juggles homework with swim practices and competitions. USA Swimming recently recognized Brooke as one of the top 20 fastest female swimmers in her age group for several events in which she competes.

The next phase of Dr. Mahone’s research will follow preschool-age children into adolescence, to identify the earliest biological signs of ADHD and determine new ways to predict which children are most at risk for the disorder.

“By following children from early in life, we hope to determine which early brain and behavioral signs are associated with later difficulties, and which aspects of early development can predict outcome and recovery,” Dr. Mahone says. “If we understand the brains of children who grow into the disorder, as well as those who grow out of it, we can target preventative interventions, with the goal of reducing adverse outcomes or even reversing the course of ADHD.”

Visit KennedyKrieger.org/PreschoolADHDStudy to learn more about the study.



Brooke, now 14, participated in Dr. Mahone’s study on preschool-age children with ADHD symptoms. Brooke is one of the 20 fastest female swimmers for her age group in the U.S. in several events.

(Photograph by Jonathan Hunn/ Maryland Swimming.)



“If we can understand the brains of children who grow into the disorder ... we can target preventative interventions.”

– Dr. Mark Mahone

Aquarium Day Buoy's Spirits

Outings with Kennedy Krieger's therapeutic recreation program raise hospital patients' spirits and show them they can still go out and do fun things.

For Christopher, Demi, Elijah and Je'ani, it was not just any summer afternoon outing to Baltimore's National Aquarium. It was a chance for the teens and young adults—all inpatients at Kennedy Krieger Institute this past summer—to practice being mobile in the real world, before leaving the Institute to go back home.

The Institute's therapeutic recreation program, which focuses on improving patients' mental and physical health, conducts one or two activities in the Baltimore area for inpatients every week, in addition to organizing activities at the Institute's hospital. The program has taken patients bowling, on picnics, to restaurants, and to the Maryland Zoo in Baltimore, among other destinations. Recreational therapists accompany every outing.

Part of the Child Life and Therapeutic Recreation Department, the program helps patients translate what they're working on in rehabilitation therapy to real-life situations. It also allows them to experience the emotional benefits that come with taking a break from the hospital setting.

For Je'ani, 13, the aquarium trip was an entirely new experience. It was her first time away from a hospital since arriving in Baltimore via helicopter earlier in the summer, after a motor vehicle crash had left her paralyzed from the ribcage down.

It was also her first time navigating the world with a motorized wheelchair.

"This trip to the aquarium is a great transition for her," said her mom, Carla. "It's a chance for my daughter to get back into the outside world again."

Recreation With a Purpose

Most patients at Kennedy Krieger's inpatient hospital work with a therapeutic recreation specialist, explains Sharon Borshay, the department's director. The specialists ensure, through fun activities and outings, that when patients return home from the hospital, they've already practiced many of the skills they'll need to live their lives as independently as possible.

"Community integration outings are key to what we do," Borshay explains. "The whole goal of rehabilitation is to get kids and young adults back to feeling like themselves again and able to navigate their way in the community."

"It's a chance for my daughter to get back into the outside world again."

— Carla, mother of Je'ani



Je'ani and her mom, Carla, enjoying the afternoon.

“The children and teens who are our patients need to know they can have fun again,” she adds. “Our outings help them, emotionally and physically, by showing that, with some accommodations and planning, most activities are still possible.”

Going home with a new means of mobility like a motorized wheelchair is a big adjustment. It means learning how to secure the wheelchair in a van, getting used to seeking out accessible entryways into buildings, moving through crowds in a new way, and getting used to being a little more visible in the community.

Christopher, 22, Demi, 21, Elijah, 14, and Je’ani rode to the aquarium in the Institute’s therapeutic recreation bus, which has removable seating to accommodate passengers in wheelchairs. The bus’s stairs offered Demi, who uses a walker, a great opportunity to practice boarding and exiting a public transportation vehicle, while its wheelchair lift made it easier for the others to board and exit with minimal assistance.

“These outings make rehabilitation more motivating and fun,” Borshay explains, “and they make it easier for our patients to accomplish goals like increasing their mobility and getting back to doing things with their friends and families.”

Above: Demi, Christopher and Elijah. Below: The Child Life and Therapeutic Recreation Department’s new bus was donated by the Women’s Initiative Network (WIN), which raises money for, and facilitates volunteerism to assist families served by, the Institute. Visit KennedyKrieger.org/WIN for more information.

A New Point of View

By the end of the outing, Je’ani was smiling and getting more comfortable with moving about in her wheelchair, especially with her new friends by her side for encouragement.

“I was nervous about her being in a vehicle again,” Carla said, “but she’s doing amazingly well.”

When Christopher, Demi, Elijah and Je’ani found the underwater viewing window for the dolphin pool, they paused to watch the dolphins swim around for a bit.

Je’ani pressed the button on her wheelchair to recline herself backward in order to see the dolphins swim back up to the surface of the water, a perspective those standing didn’t have. “I’m getting a better view,” she explained.

Christopher and Elijah reclined their wheelchairs, too, and Demi sat down on the cushioned seat of her walker.

For a few minutes, as Christopher, Demi, Elijah and Je’ani relaxed and enjoyed the view, they seemed transported to another place. The next morning, having had a taste of independence, they’d be back in the therapy gym at Kennedy Krieger, working hard toward their recovery goals, but for now, they were just four young people, enjoying an afternoon at the aquarium. – *LT*

Visit KennedyKrieger.org/TherapeuticRecreation to learn more about Kennedy Krieger’s therapeutic recreation program.



A NEW PERSPECTIVE

When Sam returned to PACT's medical child care program as an intern, he learned to see the world in a whole new way.

By Sam Noble

As a young child, I had severe asthma and life-threatening allergies. I couldn't attend a typical day care program. While my parents were at work, I needed to be near trained medical professionals in case I had a bad allergic or asthmatic attack.

That's how I ended up at PACT: Helping Children with Special Needs for the first time. PACT, which is affiliated with Kennedy Krieger Institute, is central Maryland's only medical child care center, and it was my home-away-from-home for about three years, before I started school.

This past year, my senior year of high school, I went back to PACT—this time, for an internship. I interned for a couple of hours every weekday. For the most part, I was like a teacher's aide. When I started, I knew next to nothing about working with children with disabilities, but I was keen to learn. After all, PACT had helped me survive early childhood, so I figured the chances were good it might benefit me in early adulthood, too.

Early on in the internship, I was assigned to work with Jacob, a little boy with autism. He had trouble communicating with others. I watched PACT staff members closely, to see how they interacted with children with autism. I came up with a plan.

"I loved seeing Sam's confidence in himself grow over the course of the internship."

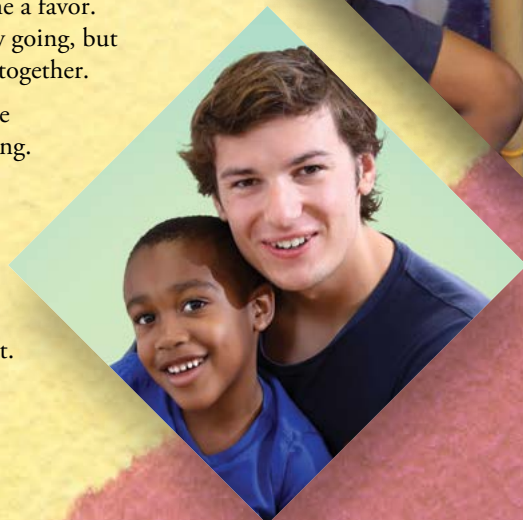
— Laura Denz, PACT

My communication skills improved so much. I think the internship helped me more than I helped the kids. I learned to see the world as I needed to see it in order to truly communicate with others.

I just entered college, and I plan to major in criminal justice, and possibly also in English. Even if I don't go on in a therapy field, the communication skills I learned interning at PACT will help me tremendously throughout my life—I am confident of that.

Visit **KennedyKrieger.org/PACT** to learn more about PACT.

Middle: Sam attended PACT from 6 months to 3½ years old, and interned with PACT as a high school senior. Top and bottom: During his internship, Sam worked closely with Laura Denz, an early intervention coordinator and pre-K teacher, and Jacob, 5.



Honoring Institute Advocate *Judy Woodruff*

It's not every day one gets to interview Judy Woodruff, so 10-year-old Ellie McGinn, who's being treated at Kennedy Krieger Institute for a genetic brain disorder, had her questions ready.

"Did your family have a good experience at Kennedy Krieger?" Ellie asked, referring to the time when Woodruff's son Jeffrey was an inpatient at the Institute following a brain injury.

"It was a difficult time ... but they did such a wonderful job taking care of [our son]," the pioneering news anchor answered. "The people there, the care he received ... the fact that they took care of our whole family, especially Jeffrey ... made all the difference in the world."

Ellie's interview with Woodruff was part of a special October 10 event, "Whatever It Takes," honoring Woodruff for her longtime advocacy for brain injury research. It was the first Kennedy Krieger event of its kind in Washington, D.C.

Woodruff's close friend and fellow journalist Andrea Mitchell also interviewed Woodruff at the event. Jeffrey's road to recovery—he went on to graduate from college, and is still a patient at Kennedy Krieger—has not been easy, Woodruff explained in her interview with Mitchell, but the Institute's "amazing physicians ... their expertise, their science, their research ... brought it all together."



Dr. Bradley Schlaggar, president and CEO of Kennedy Krieger Institute; Andrea Mitchell; Judy Woodruff; and Kennedy Krieger patients Jeffrey and Ellie.

To conclude the evening, Woodruff interviewed Dr. Bradley Schlaggar, the Institute's new president and CEO, about the future of pediatric brain disorder care and research. "Kennedy Krieger's research is changing how we treat more common conditions," he explained, as well as "rarer brain conditions and injuries. And that research is truly changing lives by changing patient trajectories."

We'd like to extend a special thank-you to the event's sponsors, including platinum sponsor CareFirst BlueCross BlueShield.

Visit [HelpKids.KennedyKrieger.org](https://www.HelpKids.KennedyKrieger.org) to watch interviews from the event and to donate to Kennedy Krieger.



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Landon uses his right hand to both catch and throw a baseball. Read his story on page 8.



WHY I GIVE

"While I was doing my rehab, I looked around the gym and thought, 'These kids deserve to have a normal, happy life.' Raising money for Kennedy Krieger doesn't feel like a chore or even a sacrifice. It's what I need to do."

— Jonathan Bresler, patient and donor

