

potential

A publication of Kennedy Krieger Institute Spring | Summer 2019

Reason to Smile

*Mother and Daughter,
Recovering Together*

Highly Determined
Patient and Medical
School-Bound

Incredible Resiliency
Serving Children in
Military Families

Looking to the Future
A Family's Quest to
Join Autism Study



Kennedy Krieger Institute



Greetings From Our President

Hello, all,

I'm looking forward to celebrating my first anniversary at Kennedy Krieger Institute this month!

During the past year, I've come to appreciate our unique organization more and more every day. Our patients, students, families, donors and staff members all contribute to our one-of-a-kind status. Patients like Caetlyn and her mom, Caryn.

Featured on the cover, Caetlyn and Caryn set an example of extraordinary courage and resilience. Severely injured in a car accident, they've been patients at Kennedy Krieger for the past three years. Their story of love and determination will inspire you, as it does me.

This issue also features two amazing young adults pursuing their dreams of becoming physicians: Chris, who has paralysis and is a former patient of the Institute, and Shannon, who has a rare bone disorder. Shannon shadowed one of our doctors at the end of her inpatient stay with us last fall.

Be sure to read about our F.M. Kirby Research Center for Functional Brain Imaging, which is celebrating its 20th anniversary. Operating behind the scenes, the center conducts specialized brain research using some of the most powerful imaging equipment in the world.

We are at an important time in the Institute's history. The number of families in need of our help is ever-growing, and your support is more important than ever. Please visit [HelpKids.KennedyKrieger.org](https://www.kennedykrieger.org/helpkids) to get involved.

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: Caetlyn is recovering from a spinal cord injury through rehabilitation at Kennedy Krieger. Read her story on page 8.

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Justin's Journey

**With a passion for paleontology,
Justin's finding his place in the world.**

By Christianna McCausland

As a docent at the Smithsonian Institution's National Museum of Natural History, Justin, 23, would spend all day with some of his favorite objects—the fossils of the museum's dinosaur collection. He'd also help museum-goers learn about prehistory by encouraging them to explore the reproduction fossils in the cart he'd roll out to the exhibit at the beginning of every shift.

It was a great way for Justin, who has autism, to be a part of society in a way that was meaningful to him and helpful to others. He's always loved learning about dinosaurs, and at the museum, he got to share what he knows with visitors from all over the world. He was so good at what he did that, in 2017, the museum presented him with an "Above and Beyond" volunteer award.

Justin's success as a Smithsonian docent was due in great part, his parents, Mary Beth and Michael, say, to his experience as a student at Kennedy Krieger Institute's Montgomery County Campus, a school dedicated to helping kids with special education needs learn and thrive.

Public school had been difficult for Justin. "His teachers didn't know how to connect with him, and he was miserable," Mary Beth says. "But at Kennedy Krieger, everything changed."

Justin was in the first class at the Institute's Montgomery County school. Now in its 13th school year, the campus has about 75 students, from prekindergarten through age 21. The school offers individualized programming that allows each student to benefit from academic, life skills and job readiness programs.

"Justin has a sense of humor, can be very engaging and has a lot of abilities," says Terry Scott, the school's education director.

"We became mini-experts on Justin and built a trusting relationship with his family, and that really benefited him."

"It was fun," Justin says of school. "They had special rooms for you to calm down and express your feelings."

The school's partnership with the Smithsonian grew almost entirely out of Justin's personal passion for paleontology. Kennedy Krieger worked with Justin for years on everything he'd need to be able to do to participate in the internship, from riding Metro trains on his own to interacting with the public.

"Justin was a trailblazer and really helped us sell this partnership to the Smithsonian, with his abilities and his exuberance for the subject," Scott says.

Justin is now enrolled in Project SEARCH, a total workplace immersion program that places participants in three consecutive 12-week internships. He hopes to have a paying job and his own apartment one day. Thanks to his education and internship experiences, it's very possible he'll meet those goals.

"I don't think we ever thought Justin would be as independent as he is now. Kennedy Krieger paved the way and opened all the doors. They always believed in him."

— Mary Beth and Michael, Justin's parents

Visit KennedyKrieger.org/SchoolPrograms to learn more about the Institute's school programs.

Far left: Justin and his sister, Lauren, exploring the multisensory room at the Montgomery County Campus school in 2008. Left: Justin and Lauren share a close sibling bond. Top right: Justin and Lauren before the school's prom, which Lauren co-organized, in 2014. Bottom right: Justin at his internship at the Smithsonian's National Museum of Natural History.



Highly DETERMINED

At Kennedy Krieger, Shannon gets the treatment she needs to stay healthy, and a chance to learn more about the medical field.



loves science and is particularly interested in neonatology, which focuses on medical care for infants.

Shannon has one of the more severe forms of osteogenesis imperfecta, also known as “brittle bone disease,” a rare disorder that weakens collagen, bones and other parts of the body. She’s been a patient at Kennedy Krieger Institute for the past decade, working with specialists in a variety of fields, including bone health, audiology, neurology and physical therapy.

But her exposure to the medical field has done more than keep her healthy and thriving. “I’ve been in and out of the hospital since I was a baby. Talking with doctors and nurses, and witnessing the great things they do, I’ve always admired them and wanted to be like them one day.”

Because medical school will be rigorous, “I want to be in the best physical condition I can, so getting the best possible treatment is important to me.” That’s why she travels from Wisconsin to Baltimore a few times a year to receive care from leading experts in osteogenesis imperfecta.



“I decided at a pretty early age that I wanted to be a doctor,” says Shannon, who just turned 19 and starts her senior year of college in the fall. She

“The first time I met Shannon, I could tell right away she was a highly determined person,” says Dr. Mahim Jain, who oversees care for about 150 patients from around the world—children and adults—with osteogenesis imperfecta at Kennedy Krieger’s interdisciplinary Osteogenesis Imperfecta Clinic. “She was asking very detailed questions about her blood work, bone density and treatment. I was very impressed by how much she knew.”

That was when Shannon was 16. Over the years, she and Dr. Jain have developed a strong rapport. Together, they review her medications and bone scans and discuss potential treatments. After a DNA test revealed the genetic mutation causing Shannon’s type of osteogenesis imperfecta—Type 4—they talked about the results’ implications. “Now, I anticipate her questions so I can give her the very specific answers she’s looking for,” Dr. Jain says.

“I want to go to medical school, so getting the best possible treatment is important to me.”

— Shannon

Above: Frosty, Shannon’s service dog, keeps Shannon safe when she’s walking in public. Frosty makes sure no one bumps into Shannon, which could harm Shannon’s bones. For longer distances, Shannon uses a wheelchair, with Frosty curled up in her lap or at her feet.

Left: Dr. Mahim Jain, of Kennedy Krieger’s Osteogenesis Imperfecta Clinic, talks with Shannon in the Institute’s Therapeutic Healing Garden.

Therapy With a Shot of Espresso

This past fall, Shannon stayed at the Institute's inpatient hospital for four weeks of rehabilitation following spinal fusion surgery at The Johns Hopkins Hospital for scoliosis, a common condition for individuals with her type of osteogenesis imperfecta.

"After her surgery, we literally got her back on her feet," explains Dr. Suzanne Rybczynski, Shannon's attending physician during her inpatient stay and Kennedy Krieger's associate chief medical officer.

Shannon did several hours a day of intense physical therapy, six days a week, focusing on strength, endurance, walking and transferring in and out of her wheelchair, which she uses for long distances, explains Jenna Werner, Shannon's physical therapist while she was an inpatient.

Once Shannon was able to stand upright again, she and Werner set specific distances each day for Shannon to walk. On the day before her discharge, they walked down the street to Starbucks, where Shannon ordered her favorite coffee drink—a vanilla bean Frappuccino with a shot of espresso.

"She came in needing help just to sit up or get out of bed," Werner says. "By the time she left, she was walking down the street. She did amazingly well."

Preparing for Medical School

For a few weeks after her discharge, Shannon stayed in Baltimore for regular appointments with her specialists and outpatient physical therapy at Kennedy Krieger. During an aquatic therapy

session with physical therapist Christopher Joseph, Shannon mentioned she wanted to attend medical school and study neonatology. Thinking quickly, Joseph offered to arrange for Shannon to shadow a neonatologist before she left.

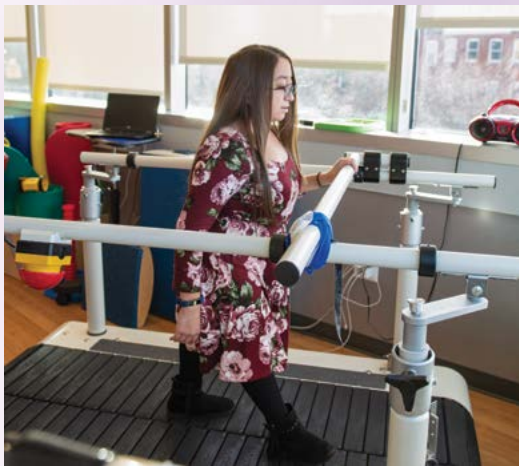
On Shannon's last morning in Baltimore, she shadowed neonatologist Dr. Marilee Allen at Kennedy Krieger as she met with patients, then debriefed with her afterward in the clinicians' lounge. "It was a really cool experience," Shannon says.

This past summer, Shannon returned to Baltimore to shadow Dr. Jain for a few weeks, joining him for patient evaluations. That gave Shannon a chance to learn more about performing physical exams and interacting with patients and families.

Shannon plans to apply to medical schools later this year, and to start med school next summer. Given her strong motivation to become a doctor and her passion for the field, "I think she'll be a great physician," Joseph says. – *LT*

Visit KennedyKrieger.org/OI for more information on the Institute's Osteogenesis Imperfecta Clinic.

Right: A variety of therapies helped Shannon recover from spinal fusion surgery last fall. Here, physical therapist Christopher Joseph assists Shannon in using an underwater treadmill to practice walking in a gravity-free environment.



Clockwise, from top left: Shannon uses a split treadmill to practice walking. Shannon and Frosty, Shannon's service dog, at Kennedy Krieger. Shannon shadows a Kennedy Krieger resident physician. Shannon develops core strength in aquatherapy with physical therapist Christopher Joseph. Shannon practices walking on a straight line with physical therapist Marianna Kogut.

Looking to the Future



By participating in a landmark study on autism, Dale and his family are helping researchers learn more about the disorder.

Left to right: Gill, Myles, Gina and Dale, who has autism and uses an iPad tablet as one medium of communication.



As Dale happily hovered in a swing during occupational therapy, his father, Gill, wondered: “Could I make one of these for Dale to use at home?”

A few weeks later, Dale, who has autism, had his very own therapy swing in the basement of his family’s home in the Baltimore suburbs. Over the next few months, Gill added a mini trampoline and other equipment to form an entire sensory circuit for Dale, 7.

“Dale’s a real sensory seeker, and needs an outlet for sensory-seeking in a controlled, safe environment,” explains Gill, an engineer. “It was really fun seeing him use the equipment at home, not just at therapy.”

Dale was diagnosed with autism at Kennedy Krieger Institute’s Center for Autism and Related Disorders (CARD) when he was not quite 2 years old. His speech and development had started to regress, and he had oral dysphagia, an aversion to things being in his mouth. Kennedy Krieger occupational therapist Myrna Pittaway worked with Dale to develop his oral and fine motor skills, and to increase his tolerance for eating different foods and textures.

“When we got the diagnosis of autism, we didn’t quite know what to think,” says his mom, Gina, a teacher. “We’d had all these plans for him when he was born.”

“It was a hard day, not knowing what the future would hold,” Gill adds.

But Gina and Gill decided to look the future squarely in the face. They read up on autism, asked questions during Dale’s therapy sessions, and became experts on their son. They shared what they learned with family members to increase Dale’s circle of support. Dale continued with his therapies—at Kennedy Krieger and at home—and started attending a nearby preschool for children with autism.

And Gina and Gill kept an eye out for research studies on autism that Dale could join. They wanted not just to help Dale, but to take part in something that could ultimately help all individuals with autism. About two and a half years ago, they learned about SPARK.

A Landmark Study

SPARK—short for Simons Foundation Powering Autism Research for Knowledge—is a research project recruiting 50,000 families to study the genetic basis of autism. Kennedy Krieger is one of 33 sites around the country facilitating DNA collection for the study by recruiting families to participate, and helping families register and collect DNA samples.

Each participating family sends in a tube of saliva for each biological parent, and for their child with autism. If the child has a full brother or sister who does not have autism, the family may send in a tube of saliva for that child as well. The DNA extracted from the saliva will help researchers better understand the causes and full spectrum of autism in order to develop and target therapies for the disorder, explains Bonnie Van Metre, a research coordinator at CARD and the Institute’s project coordinator for the SPARK study.

Right: Dale's father created a sensory circuit for Dale to use at home. Here, Dale plays with a therapy swing. Below: Dale's mother, Gina, helps Dale, a sensory seeker, balance on a therapy ball.



Above: After completing his at-home sensory circuit, Dale rests on a giant "crash pillow." Left: Dale and his little brother, Myles, hover in a platform swing, another piece of therapy equipment good for sensory seekers.

Kennedy Krieger providers ask families who have a child with autism if they'd like to learn more about the study—all families with a family member with autism are welcome to participate. Typically, a family participating in the study receives its kit in the mail, spits into the tubes, and mails the tubes back to SPARK. But some kids with autism and oral dysphagia just aren't comfortable spitting into a small plastic tube. That was the case with Dale.

Part of Something Larger

For the next two years, Gill and Gina kept the SPARK study on the back burner. Dale continued to make progress with his feeding—he now eats more than 40 different types of foods—but spitting into a tube just wasn't something he was up for.

Participation in the study remained elusive until Van Metre suggested an alternative collection tool for kids like Dale: a toothbrush-like implement with, instead of bristles, a little sponge at the end. Rubbing the sponge on the gums multiple times would collect a saliva sample.

And it worked! Dale's therapies had helped him progress to the point where he could tolerate this method of collecting saliva. Almost two years to the day after their first attempt to participate in the study, Gill and Gina sent in their samples, including one for Dale's little brother, Myles.

"We knew that we had to be a part of something that has the potential to uncover findings that could help individuals with autism," Gill says. "We're very proud to be one of the 50,000 families participating in SPARK. We really believe that more needs to be done to understand autism, and the SPARK DNA research study is one of the biggest steps in that direction." – *LT*

Visit KennedyKrieger.org/SPARK for more information about the SPARK study at Kennedy Krieger.

"We're very proud to be one of the 50,000 families participating in **SPARK**."

– Gill, Dale's dad





Caetlyn and her mom, Caryn, are patients at Kennedy Krieger's International Center for Spinal Cord Injury.

Reason to Smile

Recovering from spinal cord injuries together has strengthened Caryn and Caetlyn's mother-daughter bond.

"It's raining squids! I hope you have your umbrella," says physical therapist Brooke Meyer.

"Ahhh!" Caetlyn, 7, shrieks with glee, shielding herself with her arms from the colorful suction-cup toys Meyer is tossing above her head. Caetlyn grabs the "squids" and sticks them on the tray of the stander that's supporting her body in an upright position.

"Does this go here?" Meyer asks, touching a "squid" to Caetlyn's nose.



Caetlyn giggles. "Noooo! It goes right here," Caetlyn corrects her, sticking the toy to her tray. Everyone around them in the rehabilitation gym of Kennedy Krieger Institute's International Center for Spinal Cord Injury laughs at the silliness of it all—and because it's good to see Caetlyn doing so well.

Caetlyn always loves going to physical and occupational therapy at Kennedy Krieger. "Her therapists are hilarious, and make it really fun," says her mom, Caryn. "She bounces out of therapy listing the games she won and showing me the pictures she painted. To her, therapy is something fun. For me, it's more like a workout."

As Caetlyn defends herself from the pseudo-squid, physical therapists help Caryn into an adult-size stander that's just like Caetlyn's, only bigger. Caetlyn and Caryn were injured in a car accident in November 2015—Caetlyn, then 3, with a spinal cord injury in her neck and injuries to her lungs and spleen, and Caryn with a spinal cord injury in her chest, broken ribs and a broken wrist.

Countless hours of physical and occupational therapies have allowed Caetlyn and Caryn to be able to use wheelchairs efficiently. Caetlyn still needs a back brace to help her sit up, and her hands aren't quite fully functional yet, but playing with the squid-like toys—grabbing, throwing, catching and sticking them—is helping get the nerves and muscles of her hands and fingers going again.

It's part of Caetlyn's program of activity-based restorative therapy, in which the spinal cord injury center specializes, and it's loads of fun. Caryn's therapy may be less silly, but she can't help smiling while her daughter's clearly enjoying herself.

A Board Game With Mom

After the accident, Caetlyn and Caryn were in separate hospitals, in different cities. Both needed surgery. Caryn's mom stayed with Caetlyn the whole time, traveling with her on a chartered medical flight to Kennedy Krieger.

Caetlyn stayed in the Institute's inpatient rehabilitation hospital for six months, her head bolted into a halo-shaped brace for the first four months so the vertebrae in her neck would heal. Caryn stayed in a skilled nursing facility for three months, then at a rehabilitation facility specializing in treating spinal cord injuries for another two months. After that, Caryn visited Caetlyn regularly at Kennedy Krieger.

Seeing Caetlyn in the halo gave Caryn a shock. "My once feisty little girl, who could run around, dance and sing, and do puzzles and color with her hands, now could do none of those things," she says. When Caryn was finally strong enough to hold Caetlyn on her lap, "I just hugged her and sobbed. It had been so long since I'd held her like that." >>



Above left: Physical therapist Brooke Meyer (right) drops suction cup toys on Caetlyn during physical therapy at Kennedy Krieger. A stander supports Caetlyn in an upright position. Above right: Pediatric nurse practitioner Janet Dean (right) talks with Caetlyn and her mom, Caryn, both patients at the Institute's International Center for Spinal Cord Injury.

Right: Physical therapist Lizzie Neighbors (right) helps Caetlyn balance on a therapy ball while Caryn and Caetlyn toss a beach ball back and forth during physical therapy. Below: Stenders allow Caryn and Caetlyn to stand upright as part of physical therapy. Below right: Caetlyn and Caryn share a quiet moment.



“At Caetlyn’s age, having fun in therapy is important, because that will get her to keep going back and improving.”

– Caryn



Moments to Treasure

For the past three years, Caetlyn and Caryn have each put in two to three hours of therapy a day, at home or at Kennedy Krieger. Going through the experience together, Caryn says, has strengthened their mother-daughter relationship.

“We’ve both come a long way,” Caryn says. “I’m amazed at how much energy she has now, even after being at school all day!”

For Caryn, rehabilitation is about getting her life back as a working mom of two daughters, and being able to care for them as independently as possible. Caetlyn, meanwhile, is conquering the milestones of childhood while rehabilitating her body. “For kids, rehabilitation isn’t a static thing—we’re not trying to return Caetlyn to a certain state,” Dean explains. “One of our jobs is to help her move along and meet the milestones her peers are meeting.”

Caryn now works part-time and is relearning how to drive. Caetlyn loves playing with toys and making up stories. “When we both have downtime, usually on the weekends,” Caryn says, “we play two, three, sometimes four different board games together.”

Caryn remains hopeful they’ll walk again someday—maybe with braces, or with some other technology yet to be developed. Already, they’ve regained a lot of mobility. “I think in about five years, I’ll be able to take care of Caetlyn much more than I’m doing now,” Caryn says.

As for Caetlyn, “she will finish high school, go to college, get a job and be a productive member of society,” Caryn says, “Perhaps she’ll become a lawyer—she’s so very smart!”

In the meantime, Caryn soaks up as much time as she can with Caetlyn. When they sit together, side by side or with Caetlyn in Caryn’s lap, no wheelchairs or halo in the way, Caryn’s no longer crying—she’s smiling. So is Caetlyn. “I treasure those moments,” Caryn says. – *LT*



While the halo was on, Caetlyn’s therapists worked on her arms and hands, waking up the nerves through simple exercises. Once rid of the halo, Caetlyn began strengthening her trunk and relearning how to roll over. Supported by bolsters, she sat up for longer and longer periods of time, drawing and playing games while developing core strength and balance.

Child life specialists helped Caetlyn learn about her injury and understand the treatments she was receiving. With dolls and stuffed animals, they acted out the procedures she underwent. Specialists in behavioral psychology helped her process what had happened.

One of Caetlyn’s biggest hurdles was relearning how to eat—not uncommon for someone with a spinal cord injury like Caetlyn’s, explains Janet Dean, pediatric nurse practitioner for the spinal cord injury center. Initially, Caetlyn needed a gastric feeding tube. But after two years of working to redevelop her ability to bite, chew and swallow—first with the Institute’s feeding therapists during her stay at Kennedy Krieger, and then at home—the tube came out. Now she has a healthy appetite, Caryn says.

The summer after the accident, Caetlyn and Caryn began outpatient physical and occupational therapies at Kennedy Krieger. At one of their earliest sessions, Caetlyn choose a board game for the two to play together. While they played, Caetlyn—with Meyer’s help—sat on a large therapy ball.

“From a therapy standpoint, we were focusing on Caetlyn’s balance, but for Caetlyn, it was ‘I get to play a game with Mom now,’” Meyer says.

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

MAKING MOVIES OF How the Brain Works

At the F.M. Kirby Research Center, powerful magnets and cutting-edge imaging technologies let researchers study the brain in action.



What weighs 60 tons, sits in the basement of Kennedy Krieger Institute, has a magnetic field about 140,000 times stronger than that of Earth, and is one of the most important tools for brain research in the country?

If you said “Kennedy Krieger’s giant magnet,” bingo!

About the size of a minivan, the magnet is part of the 7T fMRI scanner at the Institute’s F.M. Kirby Research Center for Functional Brain Imaging. The “T” is for “Tesla,” a unit used to measure the force of a magnetic field, and “fMRI” stands for “functional magnetic resonance imaging,” explains Terri Brawner, the center’s chief fMRI technologist.

Founded 20 years ago as a collaboration between Kennedy Krieger and The Johns Hopkins University School of Medicine’s Russell H. Morgan Department of Radiology and Radiological Science, the Kirby Center is dedicated to supporting brain research. Its neuroimaging equipment is used regularly by researchers from across the Institute, The Johns Hopkins University and the University of Maryland, and technologies developed at the center are used by researchers from all over the world, says Dr. Peter van Zijl, the center’s director.

“The center is a major feature of the scientific fabric of Baltimore, and is truly a valuable and integral space for innovation and collaboration that, as far as I am aware, is unparalleled,” says Dr. Bradley L. Schlaggar, president and CEO of Kennedy Krieger.

The 7T scanner’s powerful magnetic field allows researchers to make “movies of the brain” by detecting changes in blood oxygenation, explains Dr. James Pekar, the center’s manager and research coordinator. This lets



researchers see what areas of the brain are active when a person is, say, reading a book, looking at a photo of a loved one, or at rest. What researchers learn with the scanner can have far-reaching implications for developing treatments for individuals with disorders and injuries of the brain.

The center also has two 3T MRI scanners that can also detect blood oxygenation changes. Using the 3T scanners, Kennedy Krieger research scientists Dr. Mary Beth Nebel and Dr. Stewart Mostofsky, director of the Institute’s Center for Neurodevelopmental and Imaging Research, discovered that communication between the regions of the brain controlling vision and movement is reduced in children with autism compared to their typically developing peers, and that this disruption in communication is predictive of how much difficulty they have with socialization and communication. Dr. Nebel and Dr. Mostofsky are now investigating how this discovery can inform new therapies for individuals with autism.

“The Kirby Center serves the collaborative, scientific community of Baltimore and the world. That’s something to be celebrated and championed.”

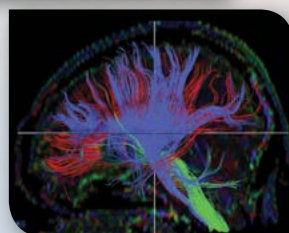
– Dr. Bradley L. Schlaggar

The center’s scanners can also be used to create extremely detailed, three-dimensional scans of the brain. The Kirby Center was the first to develop axonal tracking to map the human brain, and its “MRI Atlas of Human White Matter,” published in 2005, comprises one of the first comprehensive sets of illustrations of connections in the living brain.

“The innovation happening at the center makes it possible for us to understand more deeply the biological mechanisms of both common and rare neurological conditions,” Dr. Schlaggar says. “That deeper knowledge will allow us to advance our diagnostic and therapeutic approaches to treating disorders and injuries of the brain, making the center integral to furthering Kennedy Krieger’s mission.” – *LT*

Visit KennedyKrieger.org/KirbyCenter for more information about the center.

Above left: This magnetic resonance angiogram, developed at the Kirby Center, delineates arteries of the head and neck. Far left: MRI technologist Kathleen Kahl prepares a child for a brain scan at the Kirby Center. Middle left: Dr. James Pekar (standing) and Dr. Peter van Zijl watch a brain scan in process. Close left: A scan of some of the white matter connections in the brain, created by MRI technology developed by researchers at the Kirby Center.





Incredible Resiliency

Kennedy Krieger's Behavior Health Services for Military Families help children in military families manage the unique challenges they face.

Dr. Jennifer Crockett knows what it's like to be part of a military family. For more than two decades, while her husband served in the U.S. Army, they and their children moved every few years. In the early 2000s, her husband was deployed twice to Iraq. She understands the effects a parent's deployment to a combat zone can have on children.

"As a whole, children in military families face a set of challenges that their peers in civilian families don't," she says. "They move, on average, every two years. They're often separated from a parent for a long time. A parent may experience an injury during deployment. All of that can lead to stress, anxiety, depression and behavioral difficulties. But that's where we can be of help."

Ten years ago, Dr. Michael Cataldo, director of Kennedy Krieger Institute's Department of Behavioral Psychology, began developing the Institute's Behavior Health Services for Military Families for children with one or both parents serving in active duty or the reserves, or retired from the military. He selected Dr. Crockett, director of training for the department, to direct the new program based on her familiarity with military life. The Institute's first military behavioral health clinic opened in 2013 in Odenton, Maryland, just a few miles from Fort George G. Meade, a major U.S. Army installation. It now serves close to 1,000 military-connected families a year. Services are also provided at Kennedy Krieger's Columbia, Maryland, clinic.

All of the program's psychologists are trained and experienced in working with military families. "When a military family visits us, they can focus on the issues at hand, without first having to explain to us what their world is like," Dr. Crockett says. "The cross-country moves, deployments and even vocabulary of the military can make it daunting to see a new provider. But at Kennedy Krieger, they'll meet with providers who are knowledgeable about some of their specific challenges."

Dr. Crockett and her colleagues provide services for a range of diagnoses, including behavioral disruption, ADHD, anxiety and depression. "The most common challenge I run into is when one of two caregivers is deployed, and the other has to assume all caregiving responsibilities," says clinical psychologist Dr. Lauren O'Donnell, who works primarily with younger children. "This can lead to changes in the structure and routine of the home,

"When a military family visits us, they can focus on the issues at hand, without first having to explain to us what their world is like."

— Dr. Jennifer Crockett



discipline strategies, and the amount of attention that caregiver is able to provide to their children. These changes can be hard on children.”

“And school systems can be drastically different in different regions of the country,” adds clinical psychologist Dr. Christi Culpepper, who works mostly with older children. “Some kids move and find their new classes are following a different curriculum, and some kids who’ve been granted academic accommodations at their previous school find they could benefit from different accommodations in their new school environment.”

Over the past five years, the program has trained more than 30 postdoctoral fellows. Many have gone on to work in clinics across the country. “I’m so proud of our fellows, who have gained so much knowledge about the military and are excited to continue working in the field,” Dr. Crockett says.

Serving Children in Military Families

For Amanda and Todd, preparing their three children, Addison, 14, Reagan, 11, and Thomas, 8, for the various moves they made during Todd’s career with the U.S. Air Force was an unexpected challenge. Both had stayed put in their hometowns growing up, and didn’t quite realize the stress that moving every few years had on their children.

A couple of years ago, Addison was referred to Kennedy Krieger and started working with Dr. Culpepper. When Amanda and Todd, now retired from the Air Force, saw how much that helped Addison, they arranged for Reagan and Thomas to work with Dr. O’Donnell.

From their family’s work with Drs. Culpepper and O’Donnell, Amanda and Todd learned that military life amplified the normal anxieties of growing up. “Todd and I have changed how we interact with the kids,” Amanda says. “Now, we talk with each child about what triggers stress and anxiety, and we help them recognize those triggers in each other.”

Growing up in a military family has its benefits, though. “I think the kids have a much broader view of the country,” from living and going to school in so many different states, Todd says.

And all the changes they experience cultivate an incredible resiliency. “Children in military families are ‘bounce-back kids’—their experiences make them stronger and better able to handle things when they happen,” Dr. Crockett says.

“The sacrifices military families make to protect our country are significant. We see what they go through—we know the children serve right alongside their parents. It is truly an honor to serve them.” – *LT*

Visit KennedyKrieger.org/Military for more information on the Institute’s Behavior Health Services for Military Families.



Left: Dr. Christi Culpepper (left) talks with Addison (right) and Addison’s parents, Todd and Amanda (center), during a therapy session.

Below: Todd, Amanda, Addison and Dr. Culpepper play a board game during the session.



Left: Dr. Lauren O’Donnell uses military action figures to talk about military life with Thomas and Reagan during a therapy session.

Below: Thomas colors with Dr. O’Donnell during the session.



Below: Dr. O’Donnell leads Reagan and Thomas in a creative activity during a therapy session, while Amanda and Todd look on.





NO LIMITATIONS

By Chris Connolly

*At Kennedy Krieger,
I learned I could
accomplish more than
I thought possible.*

After experiencing a spinal cord injury as a teenager, it seemed as though other people expected less of me. Luckily, my family has been with me every step of the way and has never given me an inch.

The attitude at Kennedy Krieger Institute's International Center for Spinal Cord Injury resonated with us. Its message was inspiring and gave me hope: If I was willing to work hard, I could accomplish anything.

As much as I craved a normal life after my injury, I knew that aggressive and progressive rehabilitation had to be my focus in the short term. At Kennedy Krieger, where I did two months of inpatient rehabilitation and a few rounds of outpatient therapy, I juggled my education remotely. Hours of intense physical and occupational therapy every day were followed by schoolwork all evening.

I always played a lot of sports, but after my injury, therapy and academics took their place. Throughout the remainder of my high school career, I spent all of my free time either working on my physical health or studying.

To say it was hard is an understatement. I remember thinking everything I was up against was difficult and impossible. However, my experience at Kennedy Krieger taught me that I could accomplish more than I thought possible.

When I learned I was accepted at Stanford University, I realized all of the sacrifices were worth it. I still had a lot of self-doubt about whether I could handle the physical and academic challenges, but my family encouraged me to take it one day at a time. I earned my bachelor's and master's degrees, graduated as a member of Phi Beta Kappa, and was a finalist for both the Rhodes Scholarship and the Marshall Scholarship.

By the end of college, I had set my sights on medical school, and I knew I could handle it academically. What I didn't know was whether there would be a school progressive enough to work with me, as most medical schools have physical criteria for applicants.

Today I'm a student at the University of Michigan Medical School. I just finished my surgery and OB-GYN rotations. Although I may do things slowly or differently, I've been able to do almost everything. My experience so far hasn't been much different from that of my peers. I've sutured, helped deliver babies and, importantly, built a good rapport with my patients.

While I enjoy clinical work, I intend to have a non-traditional career in medicine. I've always loved making things, and I recently filed

a patent for a 3D printable cardiology stethoscope handle that helps individuals with limited dexterity perform physical exams. In the future, I plan to continue creating devices that help people with disabilities pursue their careers.

I realize many people with disabilities may experience uncertainty and, at times, self-doubt. I believe you can transcend any limitations others put on you—just don't put limitations on yourself.

Visit [KennedyKrieger.org/ICSCI](https://www.kennedykrieger.org/ICSCI) to learn more about the International Center for Spinal Cord Injury.

I realize many people with disabilities may experience uncertainty and, at times, self-doubt. I believe you can transcend any limitations others put on you—just don't put limitations on yourself.

30th Annual

Festival of Trees
KENNEDY KRIEGER INSTITUTE
NOVEMBER 29 - DECEMBER 1, 2019

Plans are quickly coming together for Kennedy Krieger Institute's 30th annual Festival of Trees, the largest holiday-themed festival of its kind on the East Coast. The 2019 event will be held Thanksgiving weekend, November 29 through December 1, and will once again serve as the unofficial kickoff to the holiday season. Be a part of the fun by:

- * Sponsoring the event
- * Volunteering at the event
- * Entertaining the crowds from onstage
- * Designing a tree, wreath or gingerbread house
- * Donating an item for the silent auction
- * Providing shopping opportunities as a vendor

For more information about the 30th annual Festival of Trees, visit FestivalofTrees.KennedyKrieger.org or call 443-923-7300.

SAVE THE DATES!

Friday, September 13, 7 to 10 p.m.

The Fall Fête fashion show, to benefit children and families served by Kennedy Krieger

Monday, October 7, all day

National Capital Region Security Forum Charity Golf Tournament, to benefit Kennedy Krieger's Center for Brain Injury Recovery

Saturday, October 19, all day

Join Kennedy Krieger's Baltimore Running Festival Charity Team to support the Institute's rehabilitation programs

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



Lions, Tigers and ROAR—Oh My!



Nearly 1,000 participants ROARed like lions at ROAR for Kids, Kennedy Krieger's annual outdoor spring fundraiser, on Saturday, April 27. With its fun jungle theme, the event raised more than \$105,000 for the Institute as families enjoyed the 5K run, low-mileage walk and Jungle Festival. Congratulations to Landon Brown, who won the annual ROAR for Kids Cara Becker



Youth Fundraising Award for the third year in a row, by raising \$3,723 for the Institute this year! A big thank-you goes to all of our sponsors, participants and volunteers who helped make this event a ROARing success. Visit the gallery at KennedyKrieger.org/ROARpics to see photos from the event.



Hats & Horses Raises Funds for Pool Renovation

The fourth annual Derby-themed Hats & Horses event raised more than \$430,000 to support the renovation of Kennedy Krieger Institute's Greenspring Campus pool, used daily by Kennedy Krieger programs such as LEAP (Lifeskills and Education for Students with Autism and other Pervasive Behavioral Challenges) and the Bennett Physically Challenged Sports Program. Nearly 300 guests attended the May 3 event, which included dinner, dancing, and silent and live auctions. Hats & Horses is organized and hosted by the Women's Initiative Network for Kennedy Krieger.

Please visit KennedyKrieger.org/WIN for more information.





Kennedy Krieger Institute

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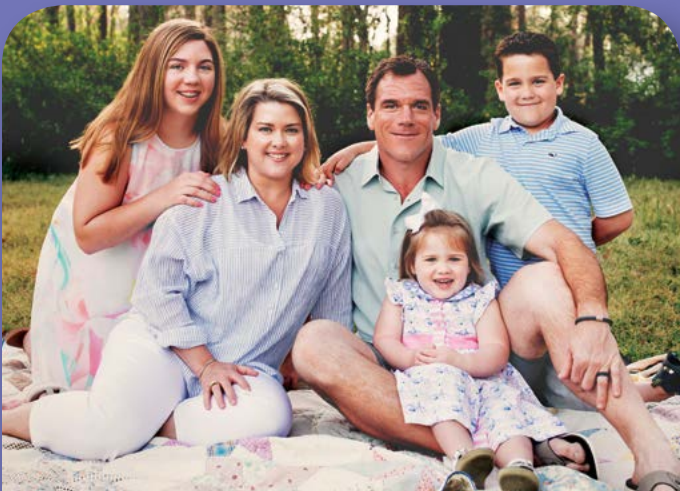
Your support helps amazing patients like Caetlyn and her mom, Caryn.

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

Visit KennedyKrieger.org/PS19 to make your donation today!



Caetlyn and her mom are recovering from spinal cord injuries together at Kennedy Krieger. Read their story on page 8.



WHY I GIVE

“We’re just so glad to be able to help other children who, like Anabelle, are living with Sturge-Weber syndrome.”

– Julie Faneca, donor

Anabelle, Julie, Alan, Penelope and Burton Faneca. Julie and Alan have funded two clinical trials of treatments for Sturge-Weber syndrome.