

LEADERS IN *Care*

STORIES OF THE MOST AMAZING CARE ANYWHERE

SPRING 2026

A Drive to *Succeed*

Young patients reach their goals with
help from caring, skilled specialists



Shriners
Children's™



OUR MISSION

At Shriners Children's™, our three-part mission has one goal: to change and improve lives. We do this by caring for our patients, conducting research to gain knowledge and develop new treatments, and providing educational opportunities for physicians and other healthcare professionals.

WHO DO WE TREAT?



Children under age 18 may receive care and treatment when there is a reasonable possibility they could benefit from the specialized services we offer. All services are provided regardless of a family's ability to pay or insurance status.

WHAT ARE OUR PEDIATRIC SPECIALTIES?



- + Treatment for orthopedic conditions
- + Burn care
- + Spinal cord injury rehabilitation and management
- + Cleft lip and palate care

GROUNDBREAKING RESEARCH



We strive to discover answers that will one day improve lives. Our innovative researchers have made significant breakthroughs in all four of our service lines, improving patient care and adding to the global body of medical knowledge.

CONTINUING EDUCATION



One way we help improve the lives of children worldwide is by offering educational opportunities to medical professionals. We maintain relationships with several medical teaching facilities, and our clinicians are known for sharing their experience and knowledge with other medical communities.



THE SHRINERS FRATERNITY

Shriners International, a fraternity based on fun, fellowship and the Masonic principles of brotherly love, relief and truth, founded Shriners Children's as its official philanthropy in 1922. What began as one hospital is now a world-renowned healthcare system with locations in three countries. The fraternity, which has approximately 200 chapters in several countries and thousands of clubs around the world, continues to support this unique healthcare system. To learn more, please visit shrinersinternational.org.

COMMUNITY CONVERSATIONS

Dear Readers,



As spring unfolds with its promise of renewal, I find myself reflecting on the profound meaning of “firsts” in childhood.

New parents are always eager — sometimes anxiously so — for their children to reach those anticipated milestones. That first smile, first word, first step. We understand that rush of excitement because at Shriners Children’s, it’s no different. Our staff celebrates each patient’s firsts with the same joy and anticipation any parent feels.

In this issue, our feature on page 17 explores these universal childhood milestones and why they hold such significance. But at Shriners Children’s, we witness first moments that are hard-won with determination, medical expertise and unwavering hope.

When a child takes their first independent steps after surgery or runs on a new prosthetic leg, these breakthroughs carry the weight of countless therapy hours and the resilience of extraordinary young patients. Their courage inspires us daily — from learning to communicate in entirely new ways to achieving independence that transforms lives.

I hope you will enjoy our story on page 11 and discover how one patient is sharing her journey with thousands of online followers, turning personal triumph into powerful advocacy. These stories remind us that finding your voice can be deeply meaningful.

Here’s to new beginnings and the unstoppable spirit of childhood.

Sincerely,

Mel Bower
Chief Marketing and Communications Officer
Shriners Children’s

This letter from April, mother of Shriners Children’s Chicago patient Evan, shows that caring is not only about the medicine — it’s about taking time to make everyone feel comfortable and special.

Dear Dr. Davis-Sandfoss,
We had the privilege of meeting you and having you as Evan’s anesthesiologist during his ear tube procedure. From the moment you entered the room, you brought such a presence of peace and comfort to my mama heart. I think I even told you, “I’m more worried about you keeping Evan safe and alive.” (I say that to every anesthesiologist.) Your compassion and kindness to Evan was out of this world. From you offering to show him the mask, to asking if he wanted me to be in the room with him for a little bit, to your bright smile, and your genuine, natural, caring demeanor. You are definitely ONE OF A KIND!
So, THANK YOU!
Thank you for your compassion.
Thank you for your kindness.
Thank you for being so genuine.
Thank you for bringing more sunshine into the room. (as it was already a sunny day)
Thank you for your thoroughness.
Thank you for your mommy heart.
Thank you for keeping our baby boy safe.
Thank you for being YOU!

Sincerely,
April (Evan’s mom)



SPRING 2026

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 **VISIT US ONLINE** to find more stories like these at myleadersincare.com.

ON THE COVER: After an accident that required his foot to be amputated, Owen came roaring back with strength and spirit.

Shriners Children’s Researcher Receives NIH Grant to Study Foot Deformities

Karen Kruger, Ph.D., a biomedical engineer and research director of the motion analysis center at Shriners Children’s Chicago, has been awarded a \$3.2M research grant from the National Institutes of Health (NIH) to study flatfoot deformities at three Shriners Children’s locations over a five-year period.

Medically speaking, flatfoot occurs when the middle of the child’s foot touches the ground, when standing, instead of just the toes and heels. Most kids are born with flat feet and their arches develop as they grow. In about a quarter of children, the arch doesn’t develop correctly by age 6 — but many of these kids still have no issues playing, running and jumping.

“A lot of those children will be asymptomatic, but a subset goes on to develop pain and a collapsed arch,” said Dr. Kruger. However, children with neuromuscular conditions may be more likely to experience complications when low or high muscle tone

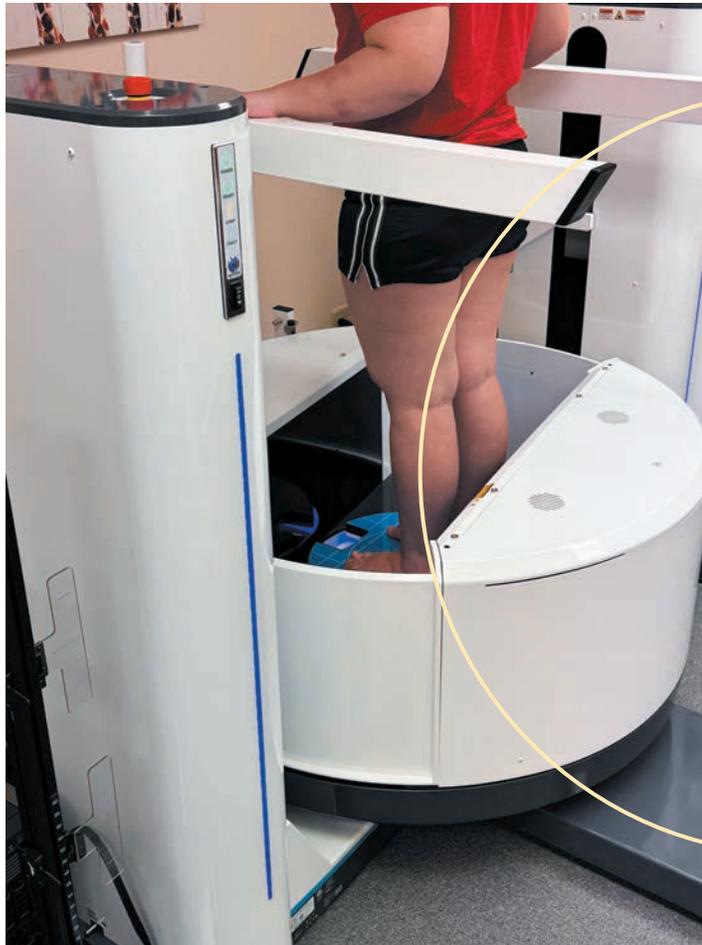
related to their diagnosis doesn’t allow them to compensate for foot deformities. “In children with cerebral palsy, problems with flat feet may be as high as 60% to 70%,” said Dr. Kruger.

The study involves a new diagnostic tool called weight-bearing computed tomography or weight-bearing CT, which provides 3D imaging of the children’s feet. These 3D scans will offer an analytical advantage for pediatric patients whose feet are still growing. Currently, 2D X-rays cannot offer enough visualization of growth plates, which makes analysis more complicated.

This is Dr. Kruger’s first NIH grant as a principal investigator. “Dr. Kruger’s hard work and tenacity have paid off,” said Ross Chafetz, PT, DPT, Ph.D., MPH, corporate director of motion analysis centers. “She is a leader both nationally and internationally, and we are proud to have her represent Shriners Children’s.”

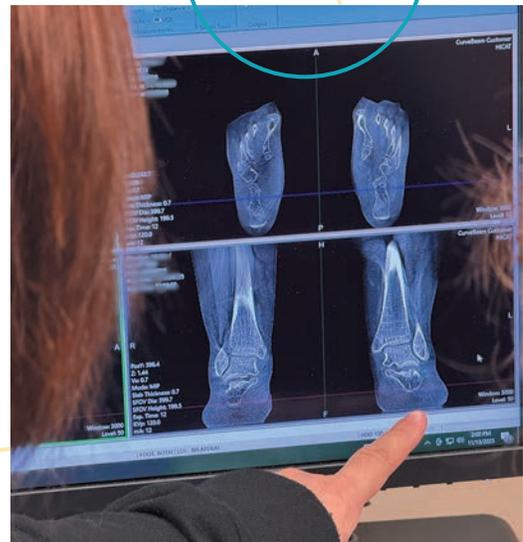


Karen Kruger, Ph.D.,
Shriners Children’s Chicago



“In children with cerebral palsy, problems with flat feet may be as high as 60% to 70%.”

— KAREN KRUGER, PH.D.



expertise
& EXCELLENCE

SPECIALTY CARE FUELED BY INNOVATION & RESEARCH

A Drive to Succeed

*Surgeons, prosthetists
and physiatrists use their
remarkable skills to help
kids pursue their dreams*

*Thanks to the outstanding
care he received at Shriners
Children's Chicago, Owen
is enjoying life — and his
spot on the golf team.*

Shriners Children's physicians are known for their expertise in treating children with complex and rare orthopedic issues. As medical care has advanced, our orthopedic focus has expanded to meet new and greater demands. Many locations are now the local leaders in fractures, sports injuries and follow-up care for childhood orthopedic conditions — including the occasions when an amputation is required.

In 2013, Owen, then 3, was airlifted to a level-one trauma center in suburban Chicago after he sustained a traumatic amputation of part of his foot in a lawn mower accident. The serious injury required surgery within the first 24 hours to stabilize the limb and preserve as much healthy tissue as possible. >>

Owen was immediately seen by pediatric orthopedic surgeon Terri Cappello, M.D., who said that in trauma situations, training and instinct work together to determine the best course of action. Dr. Cappello performed a rare ankle disarticulation — known as a Syme amputation — which removes the foot at the ankle while preserving the heel pad to create a weight-bearing limb for a specialized prosthesis. She has performed this procedure only twice in her 25-year career.

“I had to move the tissues that were no longer going to be useful. In doing so, I removed all the bones of his foot but was able to save some skin and soft tissue on the bottom to close the traumatic wound,” Dr. Cappello recalled. “The damage to the skin is important, because you have to have skin to cover the amputation. You can’t walk on a skin graft; you need to walk and bear weight on normal skin.”

Because Owen would require long-term specialized orthopedic and prosthetic care as he grew, Dr. Cappello knew right away she would be referring this young boy to Shriners Children’s for follow-up care.

Change of venue

As Owen recovered, Dr. Cappello recommended the family see Jeffrey Ackman, M.D., at Shriners Children’s Chicago.

“I knew that the orthopedic surgeon, as well as the orthotist and prosthetist had the most experience in the city, and that’s what I wanted for Owen. Nowhere except Shriners Children’s, in my opinion, had the ability to care for this patient postoperatively.” Owen’s family followed that advice and brought him to Dr. Ackman, who has the busiest pediatric amputee clinic in a six-county area.

Over the years, Owen has received 11 prosthetic legs that allowed him to play, jump and keep up with his classmates. Today, Owen is thriving as a happy,

confident young man — a ninth grader who recently made the high school golf team.

Joining a winning team

Dr. Cappello now practices at Shriners Children’s Chicago. She joined the institution to expand the location’s general orthopedic practice and fracture clinic and to provide specialized education to referring pediatricians.

When Owen, his mom, Carrie, and the family learned Dr. Cappello now works at Shriners Children’s, they came into the hospital for a reunion. Dr. Cappello enjoyed their gift of a beautiful flower bouquet, but the true highlight was seeing this confident young man.

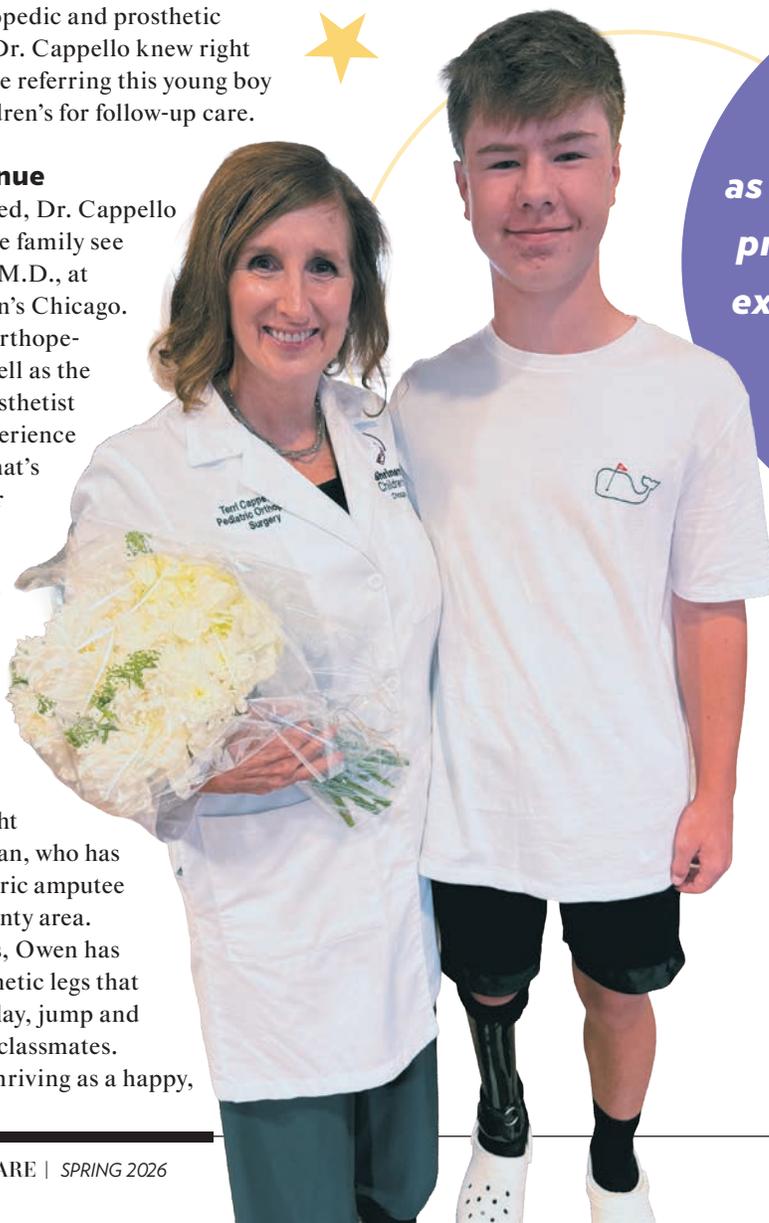
“It was just so good to hear that he’s physically and emotionally doing well. Seeing how well Owen is doing supported my instinct that Shriners Children’s was

the right place to send him. Dr. Ackman’s expertise has helped him reach all of his goals,” Dr. Cappello remarked.

Independence Day for Mariah

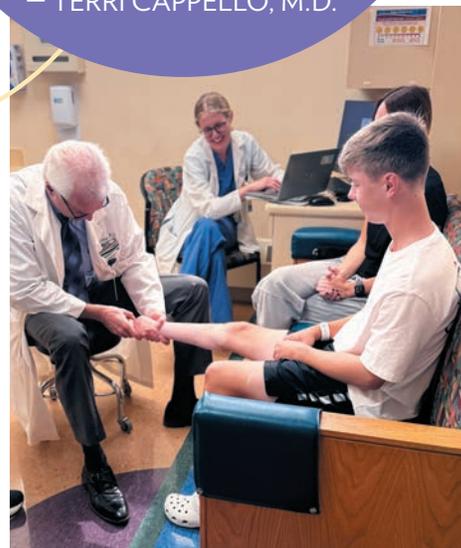
Mariah was born with a severe leg length difference resulting from an underdeveloped lower leg. As a young child, she required three different foot surgeries because of the way her movement was impacted. Following the care plan of her orthopedic doctor near their home in New York, Mariah’s parents, Cassandra and Charles, were prepared for her to undergo a leg-lengthening procedure during adolescence. However, when that provider retired, Mariah’s new doctor no longer advised the same treatment. The family didn’t know where to turn.

By this time, Mariah was 11, and her condition significantly limited her activity level.



“I knew that the orthopedic surgeon, as well as the orthotist and prosthetist, had the most experience in the city, and that’s what I wanted for Owen.”

— TERRI CAPPELLO, M.D.



Owen’s surgeon, Dr. Jeffrey Ackman, left, is one of the leading specialists on pediatric amputation in the area.

“She couldn’t play sports and had back and hip pain. If she walked long distances, she would get very tired and had to take frequent breaks,” said Cassandra. “Mariah started losing her confidence because she couldn’t keep up with her friends.”

Concerned and seeking a second opinion, Cassandra found the Shriners Children’s website and called immediately. She and Charles were happy to get an appointment right away at Shriners Children’s New England in Springfield, Massachusetts, with orthopedic surgeon and medical director Lael Luedtke, M.D.

At the conclusion of Mariah’s exam, Dr. Luedtke delivered some unexpected news: She determined the best course of action was to amputate Mariah’s foot and then fit her with a prosthesis, evening her leg length and improving her mobility. Mariah and her parents were shocked.

The family took several months to consider their next step, but with the help of her parents, Mariah weighed all the pros and cons and decided to move ahead with the amputation.

The care team at Shriners Children’s provided Mariah with support and reassurance every step of the way. “When Dr. Luedtke walked into the room on the day of the surgery, she knew we were nervous,” recalls Cassandra. “She told us to think of it as ‘Independence Day,’ because that was what Mariah would gain from the amputation. That just changed our perspective on everything.”

Once Mariah healed from surgery, she saw Eunice Wong, MSOP, CPO, a prosthetist with Shriners Children’s New England’s Pediatric Orthotic and Prosthetic Services (POPS), to be fitted for a prosthesis. When Mariah walked with it for the first time, she immediately felt a difference. “It was life changing,” described Mariah. “I never realized I had that much pain until I started walking again and noticed my hips didn’t hurt.”

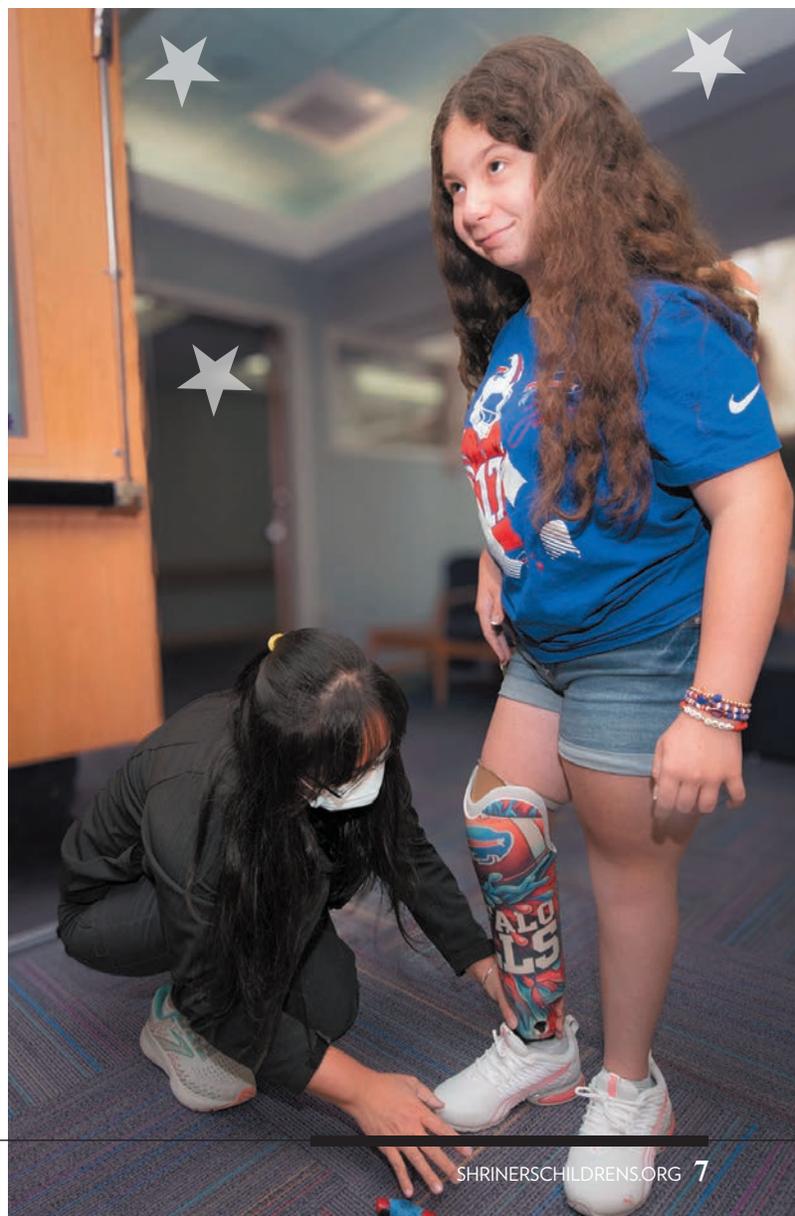
Having their entire orthopedic care team assembled in one place has given Mariah’s family peace of mind. “Mariah walks into Shriners Children’s and everyone knows her,” said Cassandra. “They make it a point to remember each individual family, something you don’t see elsewhere. Everyone involved in her care makes us feel like our decision was the right one every time we’re there.”

The function specialist

Mariah also received care from an additional specialist, Shriners Children’s New England physiatrist Jennifer Earle Miller, M.D. Dr. Miller works alongside her colleagues in orthopedics, POPS, and physical therapy to help enhance the functional ability and quality of life for patients with physical impairments and disabilities. She has expertise in the rehabilitation of individuals with amputations and limb differences, as well as cerebral palsy, spasticity, low muscle tone and other gait abnormalities.

Unlike other specialties that focus on one organ or body system, physiatry (or physical medicine and rehabilitation) is a philosophy of care that relates to the whole person. “Physiatry takes a step back from traditional diagnostics,” explained Dr. Miller. “For a patient like Mariah, >>

Below, Shriners Children’s New England physiatrist Jennifer Miller, M.D., treats children with a wide range of conditions that affect mobility. At right, Shriners Children’s New England prosthetist Eunice Wong makes final adjustments to Mariah’s custom prosthesis.



I look at their day-to-day function and assess how I can eliminate any barriers that might have a medical root to them.”

Dr. Miller’s residency training at Harvard Medical School and Spaulding Rehabilitation Hospital in Boston coincided with the Boston Marathon bombing in 2013, an experience that helped shape her career. She provided acute amputee care for survivors and helped them acclimate to the use of prosthetic devices. “It was a once-in-a-lifetime experience to have as a resident,” explained Dr. Miller. “There was no question I wanted to treat amputees in the future.”

Dr. Miller went on to work with amputees of all ages at Albany Medical Center in Albany, New York. She also created and led a multidisciplinary clinic there for children with cerebral palsy. Through this work, Dr. Miller discovered that caring for pediatric patients brought her great joy. “When I thought about taking my career to a new setting, the thing I couldn’t live without was treating children,” she said. “Shriners Children’s was the only place I envisioned starting my next chapter.”

According to Dr. Miller, physicians focus on optimizing

function rather than finding cures. They provide nonsurgical solutions that support patients at every age and stage of life. “What a patient needs today might not be the right thing for them six months or six years down the road,” she explained. “For a new prosthetic user like Mariah, I make sure the device fits her goals, is comfortable and doesn’t cause mobility issues. As she gains confidence, we continue to meet her changing needs.”

Dr. Miller also helps amputees manage symptoms like phantom limb syndrome. She prescribes adaptive seating, wheelchairs and other assistive devices, as well as nerve blocks for spasticity. “I talk with my patients about their symptoms and educate them on available options,” said Dr. Miller. “My goal is to help families live more effectively with

mastery of the information surrounding their child’s condition.”

Game-changing personalized care

Drawn to the patient-centered environment at Shriners Children’s, Dr. Miller values collaborating with other specialists. “I love having the ability to walk down the hall and ask a colleague a question,” she said. “It helps us provide the best care for patients like Mariah.”

This personalized care was evident in every stage of Mariah’s treatment, including her prosthesis. A huge Buffalo Bills fan, she worked with Eunice to create a design featuring the team’s logo. On the day her customized prosthesis arrived, Mariah celebrated both her favorite NFL team and her newfound mobility. Two months later, she attended her first-ever Bills game, an experience she’ll never forget.

Mariah, now 12, is also a huge fan of her Shriners Children’s New England team, knowing that at each visit she’ll be heard by providers who put her first. “I’m always excited to go because I’m going to see people that know me,” she said. “They don’t just talk to my parents like I’m not in the room. They ask me how I feel and that makes me happy.”



★
“I never realized I had that much pain until I started walking again and noticed my hips didn’t hurt.”
 — MARIAH, 12

★
Mariah is a huge fan of the Buffalo Bills and is overjoyed that her prosthesis is emblazoned with the team’s logo.

A Virtual Vacation

VR headsets provide pleasant distraction during painful procedures

Deep under the sea, 9-year-old Levi explores coral reefs, a sea turtle and even a shark. Levi can enjoy this adventure from the comfort of his hospital bed at Shriners Children's Ohio thanks to virtual reality (VR) technology. It's another tool Shriners Children's child life specialists use to help children cope with procedures related to their burn injuries.

"Some children don't want to watch during a dressing change or procedure, so slipping on the virtual reality goggles makes a big difference," child life specialist Kim Flood said. "VR not only blocks the sights of what's happening at the bedside but transports kids to a fun, engaging universe."

For Levi, it's about escaping to a different world. As soon as Kim places the headset, he exclaims, "Whoa! A shark!"

Child life specialist Michelle Smith said this technology allows kids to immerse themselves in a variety of experiences — from nature scenes to interactive activities.

"I like seeing the different animals under the water and how I can reach out and touch them," Levi added.

Escaping into virtual worlds reduces anxiety for many kids like Levi, but this technology isn't a good fit for every patient or procedure.



To help him manage pain, Levi, 9, engages with ocean life via a virtual reality headset.



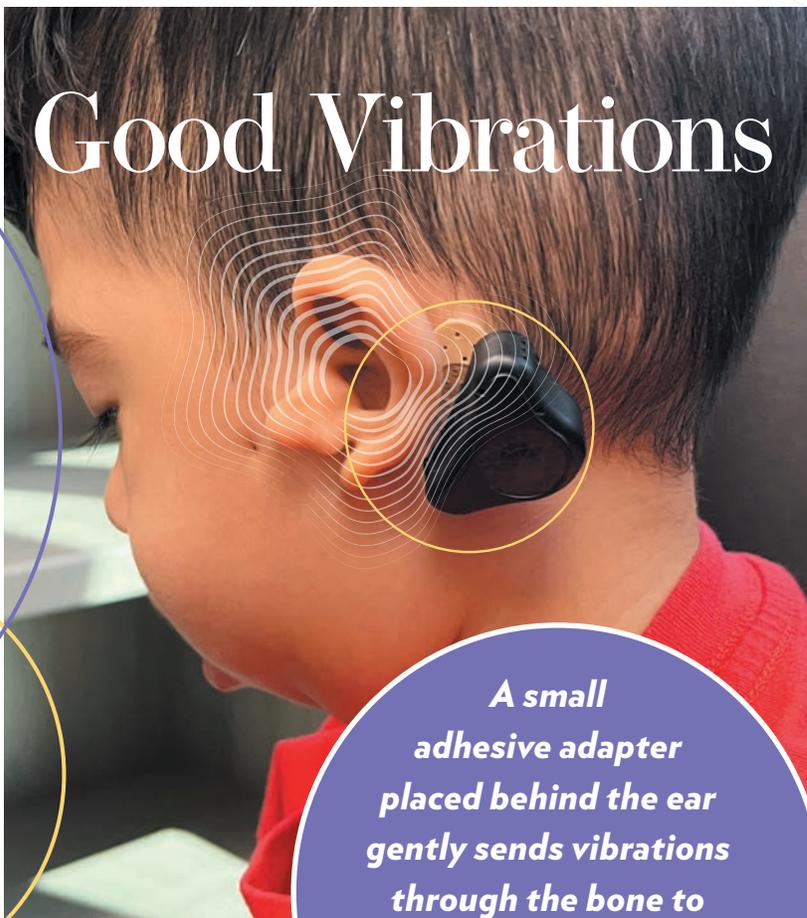
"We find VR works best with school-aged children," Michelle explained. "But not every patient can tolerate a long-term immersive experience during more painful or anxiety-inducing procedures."

Some of the most common uses for VR are relaxation for patients who fixate on pain or itching, to teach coping skills like breathing or visualization, or to promote movement. But the child life team stresses

that VR technology is just one of many tools. Every child copes differently, so the team is trained to assess their patient's unique needs and understand how they best process stressful situations.

"Our goal is to help children feel less anxious and more in control, so we're always exploring new techniques or technology that can help us do just that," Michelle said. 🧘

Good Vibrations



A small adhesive adapter placed behind the ear gently sends vibrations through the bone to stimulate the cochlea, allowing sound to be transmitted clearly.



Innovative solution brings sound to a toddler's world

When 2-year-old Josuad arrived at the Shriners Children's Texas cleft clinic, he had never heard the world around him. Born with a rare horizontal cleft and underdeveloped ear canals, he faced significant challenges with both hearing and speech.

But at Shriners Children's, Josuad found more than care — he found a team of specialists using innovative technologies. Speech-language pathologist Rachel Hogan, MA, CCC-SLP, and the multidisciplinary cleft lip and palate team developed a plan that addressed Josuad's immediate hearing needs while preserving options for future reconstructive surgery.

Pediatric plastic surgeon Phileemon Payne, M.D., ensured that tissue critical for later ear reconstruction would remain intact, expertly balancing the art of facial reconstruction with the science of hearing restoration.

Enter the magic of cutting-edge technology. Otolaryngologist Joseph Edmonds, M.D., discovered that Josuad's inner ear structures were intact — making him a perfect candidate for bone-conduction hearing technology. The team turned to ADHEAR, a safe, nonsurgical hearing solution. Unlike traditional hearing aids that require surgery or tight headbands, ADHEAR uses a small adhesive adapter placed behind the ear. The adapter gently sends vibrations through the bone to stimulate the cochlea, allowing sound to be transmitted clearly.

The device account manager Lauren Aguilarte guided Josuad and his mother through every step— fitting the device and demonstrating how to use it at home. Now, for the very first time, Josuad can hear his mother's voice, respond to sounds around him and develop speech during a critical window of brain growth — all thanks to the innovative, life-changing work happening at Shriners Children's.

At Shriners Children's, advanced technology meets unmatched expertise, giving kids like Josuad not just care, but the chance to experience the world fully.

With a new hearing device, Josuad was able to hear his mother's voice for the first time at age 2.

champions

IN HEALING

EMPOWERING PATIENTS, FAMILIES & CARE TEAMS

Ol challenges and a Bruck syndrome diagnosis aren't keeping Dominic from pursuing his interests and dreams of becoming a YouTube creator.

Brittle bone disease, a rare condition seen frequently at Shriners Children's, is a genetic disorder characterized by frail bones.

But not a fragile spirit.

On the contrary, many of our young patients with the condition are exceptionally sturdy, vibrant and irrepressible.

Dominic is one of those kids — a patient from Shriners Children's Northern California who tackles life with great fortitude and a generous nature. >>

Young patients face brittle bone disease with resolve

Calling in Reinforcements

When Dominic was just 6 weeks old, an X-ray revealed he had broken every bone in his body. This led to his immediate transfer to Shriners Children's Northern California, where he was diagnosed with osteogenesis imperfecta (OI).

OI is caused by a gene defect that affects collagen production, resulting in bones that may be deformed or break easily, which can lead to spine curvatures.

OI has been described as a chronic condition with crisis periods. Children frequently experience a lot of pain and disruption due to bone breaks. They often miss developmentally important milestones and tend to spend more time with adults rather than other children.

Strength in spirit — and outlook

Dominic's OI was further complicated by an additional diagnosis of Bruck syndrome, an extremely rare condition that combines bone fragility with congenital joint contractures (where joints are permanently bent or fixed, limiting movement). This dual diagnosis made him one of only a handful of known cases in the U.S. with both conditions.

Dominic uses a wheelchair and requires assistance with simple tasks. Yet, his spirit is indomitable.

Dominic's care has been led by a specialized team at Shriners Children's Northern California headed by Joel Lerman, M.D., and Rolando Roberto, M.D., chief of staff and medical director of the pediatric spine program. Dominic has undergone numerous surgeries, including fracture repairs and spinal procedures. When he was 6 years old, he sustained a spine and neck injury that required a halo device for stabilization.

For Dominic and his family, the hospital has become a second home. During extended stays, he enjoys music therapy and looks forward to visits from therapy dogs. The staff goes above and beyond to make him feel special, even remembering his dislike for soup.

Dominic's charisma has made him a beacon of hope for other patients. He often encourages children before their surgeries and worked with the hospital's marketing team to create a donor video during the pandemic. Dominic's dream is to have his own YouTube channel, and he's brainstorming ideas for a special teddy bear to comfort kids in the hospital.

"It's crazy to think of everything he's been through in 10 years," his mother, Lucy, said. Supported by his parents and two older sisters, Dominic continues to inspire everyone he meets, proving that even in the face of immense challenges, there is always hope.

"Dominic comes in surrounded by family — always," observes



Above, Anakalia and her parents, Krystine and Mike, value the expertise and high level of care provided by Rolando Roberto, M.D. (right) — known to patients and families as “Dr. Ro” — at Shriners Children's Northern California.

Right, senior recreational therapist Gwen Hall spends quality time with Dominic at Shriners Children's Northern California. Dominic and the care team agree — when they work together, they each get a boost.





*“I was excited
to straighten out
and be taller.”*

— ANAKALIA, 14

Dr. Roberto. “I firmly believe that gives him the reserves to inspire so many others.”

A lovely young influencer

Another patient at Shriners Children’s Northern California, 14-year-old Anakalia, is not letting OI hold her back. She has a bold spirit that fills any room she is in.

Anakalia has an Instagram page that has attracted 40,000 followers. Not bad for someone who has only been posting for a year. In her posts, Anakalia dispenses makeup advice and dances in the hospital — and her spoof of a macaroni and cheese commercial has gone viral. But importantly, she also shares her medical journey and has become an educator and voice for others with brittle bone disease.

Anakalia has OI Type III, which is generally characterized by a shorter stature, bone deformities and fractures present at birth. Painful fractures have been a frequent part of Anakalia’s life. Four years ago, a Shriners Children’s surgical team placed rods in her legs to provide strength and stability.

“I haven’t broken a bone in my legs since I got the surgery,” she said, always looking on the bright side.

Due to her OI, Anakalia’s spine had a curve. Last year, she spent four weeks in halo traction — a process that straightens the spine in preparation for a spinal fusion. True to form, after an initial adjustment to the halo, she decorated her room and filmed herself dancing in her traction walker.

“I was looking forward to this,” Anakalia said. “I was excited to straighten out and be taller.”

The results of her surgery were excellent. While her family hoped only to stop the curve from progressing, her physician, Dr. Roberto, achieved far more: Anakalia went from a curvature of almost 90 degrees to 34 degrees.

Anakalia’s mom, Krystine, is amazed by her daughter’s spirit. “I’m so proud of her and the strength she has shown throughout this journey,” she said. “We’ve never allowed her osteogenesis imperfecta to define her or limit what she’s capable of.”



Dr. Arin Oestreich's early work has shown promise to minimize some of the worst effects of OI.

OI research targets in utero bone strength

Research is a critical part of Shriners Children's mission to advance care in the conditions we treat, including OI. That commitment makes OI research and the pursuit of improved treatments part of our work.

Arin Oestreich, Ph.D., of Shriners Children's St. Louis, has long studied ways to strengthen OI bones before birth, potentially with lasting effects. Recently, Dr. Oestreich and colleagues from nearby universities received a \$3.1 million National Institutes of Health grant to support this work for five years.

The research is focused on a protein called myostatin, which regulates muscle and bone growth. The hope is that lowering the levels of myostatin during development might result in stronger muscles and bones.

"We're looking at the uterine environment and how it can influence long-term bone strength," Oestreich explained. "Our goal is to use what we learn to strengthen OI bones from the very beginning of development."

The research team has previously shown that low myostatin levels in mouse mothers produced pups with stronger bones, even in those with OI. Next, the team will examine the safety of reducing myostatin with antibodies in normal mouse mothers.

"This strategy will not cure OI, but we're hopeful that we can maximize muscle and bone strength in order to prevent fractures throughout the lifespan, and that's what this grant is all about."

Research at Shriners Children's is uncovering new ways to strengthen bones and prevent fractures in children with OI. For kids like Anakalia and Dominic, this can mean a future filled with more freedom, fewer setbacks and greater chances to thrive. 🧠

A Life Without Limits

Kids with limb differences thrive with specialized care, innovation and community

Zane sprints down the soccer field, the strut of his orthosis reacting under the force of every step. Later, he's on the basketball court, taking jump shots and weaving past defenders, pushing his custom device to its limits and sometimes beyond. Across the country, David grips a video game controller in a way that's uniquely his own, adapting to webbing between his fingers with the same ingenuity that helps him navigate daily life.

For both Zane and David, the path hasn't been about limits — it's been about possibilities. At Shriners Children's, they discovered more than medical care: They found a team that encourages curiosity, celebrates individuality and builds tools strong enough to keep up with their exceptional determination.

Full speed ahead

Born with a limb difference affecting both legs and one arm, 8-year-old Zane is breaking barriers — and orthoses — as he tackles every sport he loves. From indoor and outdoor soccer, to baseball, basketball and golf, there's nothing off limits for this aspiring professional athlete.

"When Zane says he wants to do something or be something, we

are there for it, and so is his care team at Shriners Children's," says his mom Kim.

Zane received his first orthosis from Shriners Children's St. Louis when he was just 1 and he's broken nearly every device the staff has built for him since. Turns out, that's what happens when your care team dares you to go full speed. It's a venture fully supported by the Pediatric Orthotic and Prosthetic Services (POPS) team at Shriners Children's, where they encourage their patients to just be kids.

"Zane is one of the most active patients I work with, and his determination inspires constant innovation. Every time he pushes his device to its limits, he challenges me to make it even better so he can continue reaching his goals," says Zane's prosthetist, Justin Hall, CPO.

Now on his 13th device, Zane continues to keep our POPS team busy as he reaches new milestones.

"When a device breaks or wears out, it just means the patient is using it to its

fullest potential, and I love hearing that. This also gives us feedback on how to make it better or stronger for the future, setting the bar that much higher each time. We love these kinds of challenges," says Justin.

Knowing Zane has the tools to chase his dreams as an athlete has meant the world to his moms. "We wanted to ensure Zane didn't experience unnecessary barriers to doing the things in life he wanted to do, and Shriners Children's made that happen," says his mom Betany.

Zane's current Ankle-Foot Orthosis (AFO) is a hybrid prosthesis and orthosis. "The device is dynamic, which means it bends and stores energy and spring to allow him to run fast and play harder compared to no device at all," Justin says.

He's fully equipped to tackle his goal of becoming a professional athlete, one step at a time.

"Wherever he goes in life, Shriners Children's will be an enormous part of his story," says Kim.

Confidence within his grasp

Born with webbing between his fingers due to amniotic band syndrome, David grew up adapting to the world in his own way whether tying his shoes, gripping a water bottle or mastering video game controllers. At Shriners Children's Northern California, he found not only specialized care for his condition, but a community that encouraged him to embrace his uniqueness with confidence.

David's journey with Shriners Children's began at age 1 under the care of Michelle James, M.D., then chief of orthopedics. Throughout his childhood, Dr. James and her team followed his development, offering care and guidance as he learned to navigate daily life. At 13, David chose to have surgery to release the webbing between his thumb >>

Soccer, baseball, basketball — Zane is set to tackle every sport he can!





David, left, watches as a camper engages in a dexterity game at Camp Winning Hands. As a counselor, he helped campers embrace new challenges while sharing their experiences and celebrating every achievement.

and finger. “The difference was worth it. Little things, like grabbing a water bottle, became easier,” he said.

David and Dr. James formed a bond that deepened over time, especially after they discovered a shared love of running. “We’d talk about trails, and Dr. James even encouraged me when I tackled a mountain run,” David said.

The following summer, David experienced something truly life-changing: Camp Winning Hands. This one-of-a-kind program, run by Shriners Children’s Northern California and UCSF Benioff Children’s Hospital, brings together kids with hand and upper limb differences to connect, learn and build confidence.

“Before camp, I knew other people had hand differences, but I still felt alone,” David said. “Then I got to Camp Winning Hands, and suddenly I was surrounded by kids who just understood.”

The camp’s “teen talk” sessions were especially meaningful. “That’s where we could ask uncomfortable questions and share experiences. For the first time, I felt completely understood.”

Now, David has come full circle, returning to camp as a counselor. “This year’s camp was extra special,” he said. “Seeing these kids realize they’re not alone — that’s why this place matters.”

Yuen Leung, Camp Winning Hands assistant director and Shriners Children’s nurse, witnesses that transformation every year. “The confidence they gain lasts long after camp ends,” Yuen said.

Today, David is 24, works in the federal government and is an avid gamer, having taught himself to compete at an elite level by adapting his grip on the controller.

Reflecting on his journey, David credits Shriners Children’s Northern California and Camp Winning Hands for giving him much more than medical care. “They gave me my confidence, my community and now the chance to pay that forward,” he said. “Every kid deserves to feel that kind of belonging.”

When Love Is the Reason Why

Why? It’s the shortest question, yet it sparks the deepest reflection. Why did you serve your country? Why is generosity important to you? Sometimes the answer to “why” is complex. Other times, it’s so simple it’s unforgettable.

“I’ve left all my investments, assets and entire residential estate to Shriners Children’s in my will,” says Bharat Patel, M.D., of Mooresburg, Tennessee. “It’s what my wife, Lorene, would have wanted. She passed away in 2021. I’m doing this in her memory.”

Dr. Patel came to the United States in 1968 after completing surgical training in England. Soon after immigrating, he put plans for private practice on hold to volunteer for the Air Force. As a lieutenant colonel, he used his surgical skills in service of his new country. Why? “My father told me, ‘America is your adopted homeland now — it’s your duty,’” he recalls.

After his military service, Dr. Patel and Lorene devoted their free time to traveling and volunteering. Why? “You learn so much about people and their needs when you visit other cultures,” Dr. Patel says. “It’s something we loved doing together.”

Today, at 89, Dr. Patel lives in the eastern Tennessee farmhouse where he and Lorene built their life. He speaks often with the Shriners Children’s team about his wishes. Why? “Lorene was so compassionate,” he says. “She loved volunteering, and she loved the work Shriners Children’s is doing for kids.”

A sense of duty. Compassion for others. Honoring a life shared. Sometimes “why” isn’t complicated at all. Sometimes, the answer is simply love.



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Moments



Elvin has made terrific gains over the years with help from his occupational therapist, Ashley Umali, and physical therapist, Nicole Viverito.

In pediatric rehabilitation, there are defining moments that change everything. A teenager grips a utensil for the first time after a spinal cord injury. A 4-year-old takes her first steps on a prosthetic leg. For patients like Elvin and Joy, these breakthrough moments represent more than medical milestones — they are gateways to independence, connection and possibility. >>

Finding his grip

When Elvin arrived at Shriners Children's Chicago in 2023, the teenager could barely move below his neck. He was a victim of gun violence, caught in the crossfire as a bystander. He sustained a C4 complete spinal cord injury that suddenly stripped away his independence. "I was scared when I got here. I ain't gonna lie," he recalled. "I could not feed myself, brush my teeth or even scratch an itch."

Three months of intensive inpatient rehabilitation followed, coordinated by physiatrists, physical and occupational therapists, recreational therapists, child life specialists and pediatric psychologists. Occupational therapist Ashley Umali recognized that connecting with Elvin through his interests would be key. "Music, snacks and a couple rappers," she said. "We'd play music in his room, and to practice self-feeding, we'd bring in different chips to try. We'd make things fun even though he was in a lot of pain."

The strategy worked. "They basically said, 'we're with you,'" Elvin reflected. "Nurses, doctors, cooks — everyone played a part in my recovery."

A breakthrough came in 2025 when orthopedic surgeon Felicity Fishman, M.D., performed tendon transfer surgery on Elvin, moving tendons in his arm and hand to enable him to extend his elbow and grip items. This new, literal grasp on life opened enormous possibilities. Using a universal cuff (an adaptive device that straps to his hand), Elvin now operates his laptop and phone, drives his power wheelchair, and can manage or assist with his personal care.

Hospital teacher Mary Vokoun helped Elvin re-enroll in online high school, where he discovered a talent for digital art. Now 18, Elvin has been named Student of the Month, with artwork displayed in an all-city virtual exhibition and in Shriners Children's Chicago's teen lounge. He continues outpatient therapy while finishing high school and plans to attend college online, hoping to help children as he was helped. "There is no quit in him," said Mary.

"By having a prosthesis, Joy is going to have a life like any typical kid."

— SARAH NOSSOV, M.D.



After learning to walk with her prosthetic leg, Joy approached physical therapy with fearless determination. She hasn't stopped smiling since.

Joy's first steps

The day 4-year-old Joy took her first steps with her new prosthetic leg in the hallway outside the Pediatric Orthotic and Prosthetic Services department at Shriners Children's Erie was unforgettable. Guided by Hannah Clark, MS, L/CPO, a certified prosthetist-orthotist, and hand-in-hand with her mother, Alice, Joy walked toward a lifetime of confidence and possibility.

Born with tibial hemimelia, a rare condition where the bones in her lower leg did not fully form, Joy has been receiving care at Shriners Children's Erie since she was 6 months old. After her care team determined that a prosthesis would provide the best long-term mobility, Joy underwent amputation of her left leg and began the fitting process. "By having a prosthesis, she is going to have a life like any typical kid," explained her physician, Sarah Nossov, M.D.

After months of anticipation, the moment arrived. Once Hannah confirmed Joy was pain-free and ready, Hannah guided Joy into the hallway. As Joy began to walk on two legs for the first time, she looked up with excitement and called out, "I'm walking, Momma!"

Immediately after her hallway triumph, Joy headed to physical therapy with Laurie Hudson, PT, where she kicked a soccer ball for the first time and scored multiple goals. "Watching her transition from walking with support to taking unassisted steps is an honor to witness," Laurie shared.

The family continues to receive comprehensive care at Shriners Children's Erie. "They take such good care of her," Alice shared. "They treat you like family." That sense of belonging creates an environment where children like Joy can flourish, where first steps lead to confident strides, and where possibility becomes a bright new reality. 🧡

A MODEL PATIENT

NAME: ABAGAIL

CONDITION: SCOLIOSIS

LOCATION: ERIE



“I was really nervous, but I was so happy when Hannah joined me on stage to help tell my story.”

— ABAGAIL, 13

Shriners Children’s Erie patient Abigail and her orthotist, Hannah Clark, MS, L/CPO, were recently honored on a national stage for their remarkable partnership and clinical success. In September, the pair served as keynote speakers at the American Orthotic and Prosthetic Association (AOPA) National Assembly in Orlando, Florida. Speaking before more than 500 attendees, they shared their journey, clinical approach and the impact of patient dedication in achieving life-changing outcomes.

Abigail, 13, received care for scoliosis at Shriners Children’s Erie. Hannah and Abigail’s physician, Stephen Mendelson, M.D., recognized that her severe double major curve, including a high thoracic curve, required a unique approach to treat her severe scoliosis. They ordered a custom Boston Brace 3D that was both low profile and highly effective. Unlike traditional braces, the Boston 3D applies corrective pressure on the outer side of the curve while cutting out corresponding areas on the inner side, allowing the spine to shift in the desired direction to achieve a healthier alignment. Thanks to Abigail’s dedication to wearing the brace and the customized design, her scoliosis curve has been reduced by more than 50% — an outcome that is rarely achieved.

Over the past four years, the brace has corrected Abigail’s curvature as she resumed her favorite activities, including going to school, playing with her virtual reality set, participating in gymnastics and skiing. Because her outcome was so positive, Abigail’s story can inspire other patients to wear their braces consistently. “The best brace in the world won’t work if it isn’t worn 18 to 23 hours per day,” Hannah said.

Abigail’s brace design is now being used as a model for patients with similar curve patterns. Her journey demonstrates the power of personalized care, family support and unwavering determination. She serves as an inspiration to patients, families and clinicians alike.



How High We Can Go

Activities at ShrineABILITY Camp boost confidence

Looking up at the rock wall, Jordyn felt small. She was just 7, after all. Was she too little to take on this challenge? Too weak? Too different?

With encouragement from her fellow campers and a steady hand from her dad, Jordyn timidly placed one foot on the wall, and then the other. Soon, she climbed higher than her dad could reach.

At that moment, Jordyn's bravery kicked in.

She climbed and climbed, eventually reaching the top. She peered down as loud cheers erupted. The other campers and their families couldn't hold back their excitement for Jordyn's achievement — using her single hand to climb a rock wall that stands nearly three stories tall.

That day, Jordyn conquered her fear and discovered just how high she could go.

"Getting to see Jordyn come out of her shell and really open up has been an awesome experience," explained her dad, Clint.

This experience was just one of many at ShrineABILITY Camp, a weekend event organized by Shriners Children's St. Louis for patients who live with upper extremity differences. Children and their families take on challenges like the rock wall, archery, horseback riding and canoeing. The camp environment offers a safe space for patients to build confidence in their own abilities, and for families who have children living with a hand or arm difference to find solidarity.



Jordyn, 7, front, and her brother, Jase, had a blast at a camp where they could explore their abilities.

"To watch the campers grow in their confidence in how they live their life with a limb difference, those are the moments that we do this for," reflected Michelle Cohen, OT, occupational and hand therapist at Shriners Children's St. Louis.

LOCATIONS

