

LEADERS IN Care

STORIES OF THE MOST AMAZING CARE ANYWHERE
WINTER 2024

SHRINERS
CHILDREN'S
PATIENTS
EXCEL AT THE

Paralympic Games

Former and current patients show the world what they're capable of, redefining the concept of ability



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,

Recently, a man drove five hours to Shriners Children's Northern California.



Carrying a worn stamp-collecting book, he was there to fulfill his father's dying wish.

His father, David, received treatment for spina bifida at the Shriners Children's hospital in California when he was 6 to 8 years old. A staff member gave the boy the stamp book and taught him about collecting.

Over the years, David told his sons stories about his time at the hospital. Patient beds were in big open wards, where children bonded and bickered like siblings. Surgeries were understandably scary, but recovery in an isolation ward, apart from friends, was the really hard part.

Patients today have a very different experience, as you'll read about in our feature on pages 5-7. You'll learn how our

physician-scientists are at the forefront of discovery and clinical advancements for children with spina bifida. You will read about adaptive sports like sledge hockey and therapeutic horseback riding that help kids thrive and about the wrap-around care that is one of the cornerstones of our approach to treatment.

David was 81 when he passed away, having enjoyed a long and remarkable life. Yet his connection to Shriners Children's was so strong that over 70 years later he asked his son to share his well-loved stamp book and story.

We are still offering the same hope and healing today, and our caregivers treasure the bonds they make with our patients. It is these bonds with the people in our lives that matter most. I hope together you will enjoy the love and light of the holiday season.

Sincerely,

Mel Bower
Chief Marketing and Communications Officer
Shriners Children's

PATIENT PERSPECTIVES

Staff at Shriners Children's Hawai'i were deeply moved to receive this touching note from one of their brave patients, Layla, along with a beautifully crafted tie blanket and an adorable raccoon from Layla and her sister, Joelle. Moments like these remind us why we do what we do.

To Shriners,

Hi, my name is Layla, and I'm going to be in 10th grade. I live on the Big Island and when I was 8 years old, I hurt my knee playing soccer. All the doctors here told me I broke a bone, but no one would cast me. So, I came to Shriners Children's Hawai'i. I was told (what I needed would be) taken care of, from the crutches to rehab.

At the end of all this, I got to pick out a blanket from a box. It was a red and black Minnie Mouse tie blanket, like the one in this box. I wanted to thank Shriners for its service and let someone else enjoy a blanket like I was able to.

I also crocheted a plush to match the raccoon on the blanket and was hoping they go together. My sister and I had picked out some fleece and tied all the little knots. I want to repay Shriners Children's for the kindness that they show. I am currently a cross country runner, and I play softball. I really believe that I wouldn't be able to do what I can if Shriners Children's didn't help me. Again, thank you so much, and I hope another kid will receive my blanket like I did.

Layla and Joelle



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

ON THE COVER: Patients at Shriners Children's Chicago embrace the Paralympic spirit.

Shriners Children's Sports Consortium Meets in Portland

Multidisciplinary conversations advance pediatric sports medicine care and research



Attendees of the 2024 Shriners Children's Sports Consortium developed education projects and research proposals.

Shriners Children's Portland hosted the 2024 Shriners Children's Sports Consortium this fall, bringing together a group of sports-focused pediatric orthopedic specialists to discuss sports medicine care and research at Shriners Children's. Multidisciplinary conversations centered around active research projects, sports patient-reported outcomes, motion analysis center studies, rehabilitation, education and more.

Attendees included staff from 12 hospitals and clinics — representing Shriners Children's Canada, Chicago, Erie, Greenville, Hawai'i, Lexington, Northern California, Southern California, Philadelphia, Portland, Spokane and Shreveport, plus the healthcare system's headquarters, which is in Tampa, Florida.

Jeremy Bauer, M.D., Shriners Children's Portland orthopedic surgeon and chair of the Sports Consortium group, called the meeting an inspiration. "It was an incredible opportunity to collaborate with a multidisciplinary group across our system," said Dr. Bauer. "We developed projects to help educate patients and community providers as well as research proposals that help us better evaluate return-to-sports readiness for more children beyond the walls of Shriners Children's locations."

This group, founded in 2019 by research-focused Shriners Children's medical professionals, allows incredible collaborations across the healthcare system to further research and sports medicine best practices.

The consortium was made possible by the generosity of the William E. and Thelma F. Housman Foundation. 🙏



Kyle Watterson, Ph.D., corporate director of rehabilitation, therapy services, kicks off the meeting in Portland.



LEARN MORE about sports medicine at Shriners Children's by visiting bit.ly/48kLmel.

expertise & EXCELLENCE

SPECIALTY CARE FUELED BY INNOVATION & RESEARCH

Katelyn is fiercely independent. A go-getter since she was born, the 15-year-old loves singing and dancing and has done cheerleading since she was 5 — all in a wheelchair. She is also committed to raising awareness about Shriners Children’s and advocating for kids with disabilities.

Katelyn was diagnosed in utero with spina bifida. Shortly after learning her baby’s condition, her mother, Haydee, came across a television special produced by Shriners Children’s about children with spina bifida. Haydee knew very little about the condition, but found it enlightening and reassuring.

“No one in my family knew about it,” she said. “The timing of seeing the special couldn’t have been more perfect.”

Three months after her birth, Katelyn became a patient at Shriners Children’s Northern California. >>

Katelyn was diagnosed in utero with spina bifida.

Inspiring Journeys

Innovation and compassion make Shriners Children’s a national leader in spina bifida care



Shriners Children's provides comfort

Spina bifida, a congenital birth defect, affects the formation of the backbone and can lead to damage to the spinal cord and nerves. Not all people born with spina bifida have the same needs, and the seriousness of complications can vary, so each child's treatment plan is customized.

"Shriners Children's has been a blessing for our family," said Haydee. "They have seen Katelyn grow up. She hasn't been anywhere for medical treatment but Shriners Children's since she was a baby."

During Katelyn's visits, Shriners Children's offered her everything in-house for her care. From orthopedic surgery to a wheelchair to social connections, her care team made sure she had the tools to live independently.

"They always ask, 'What does she need?' 'What does your family need?' They're always so accommodating and helpful," said Haydee.

Recently, Katelyn received special leg braces. Called a reciprocating gait orthosis, the braces help her walk independently. The sides of the orthosis are connected by a gable system, so when Katelyn moves one leg, it assists the other leg in moving properly. This makes for energy-efficient movement and offers a way for someone who generally relies on a wheelchair to practice walking movements.

Katelyn said the device gives her an amazing opportunity to feel what it's like to walk. "I love to show that kids with disabilities can do anything," Katelyn said.

Making her own impact

In fifth grade, Katelyn made bracelets to sell, raising \$500 to donate to Shriners Children's Northern California.

Along with raising awareness for Shriners Children's, Katelyn has been an active voice in her student body. She has been class



The annual clinical care meeting of the Spina Bifida Association took place at Shriners Children's Northern California.

Fifteen Shriners Children's care professionals presented at the Spina Bifida Association conference, which was attended by providers from across the United States and Canada.

president of her high school for the past three years and uses this position to advocate for other kids. One of her proudest moments was pushing for fire safety precautions that are suitable for students with disabilities. The school installed a fire safety chair to help students safely descend the stairs in case of a fire or fire drill.

"Sometimes schools don't realize certain things could be an issue. I don't want to leave my school knowing there is more I could have done for future students with disabilities," she said. "I have brought awareness to Shriners Children's, spina bifida and kids with disabilities at my school."

Shriners Children's shares its expertise

Shriners Children's Northern California recently hosted the annual clinical care meeting of the Spina Bifida Association.

"Together with the Spina Bifida Association's unparalleled advocacy and support network, we are creating a powerful alliance that ensures families receive the resources, education and medical care they need," said Shriners Children's Northern California Hospital Administrator Kenny Pawlek. "This partnership underscores our mutual dedication to empowering children with spina bifida to lead healthy, fulfilling lives."

Fifteen Shriners Children's care professionals presented at the conference, which was attended by providers from across the United States and Canada. Among many discussions, attendees heard updates on two high-profile research projects: the MOMS and CuRe trials. Diana Farmer, M.D., chief of pediatric surgery



Katelyn and her family in Sacramento, California.

at Shriners Children's Northern California, is a major investigator for both.

The Management of Myelomeningocele Study (MOMS) is a seminal study that showed the benefits of performing a surgical repair on the malformed spine prenatally — that is, before birth.

Traditionally, those born with spina bifida had their spine repaired after they were born. Before the routine use of ultrasound, the condition was never known until after the baby was born.

The MOMS trial showed that children with spina bifida who received surgery while they were still in the womb, presumably before much damage had been done to their spinal cord, had less disability.

Dr. Farmer is the senior author of the publication of the trial results.

The CuRe trial is a project of Dr. Farmer, the University of California, Davis, and Shriners Children's. Researchers are trying to determine if fetal surgery can be improved even further with the use of stem cells, which contain a "growth factor" that might help repair or protect the spinal cord.

Facilitating the transfer of care when a child with spina bifida moves from pediatric care to adult health-care was another topic at the Spina Bifida Association meeting. This topic is particularly relevant because only within the past 40 years have many individuals with spina bifida survived past adolescence.

The fact that children with spina bifida can expect to live a longer life is changing how care is delivered. The focus used to be on keeping the child comfortable, healthy and alive, but now it is on helping them thrive, too. And Shriners Children's is in a perfect position to lead the way.

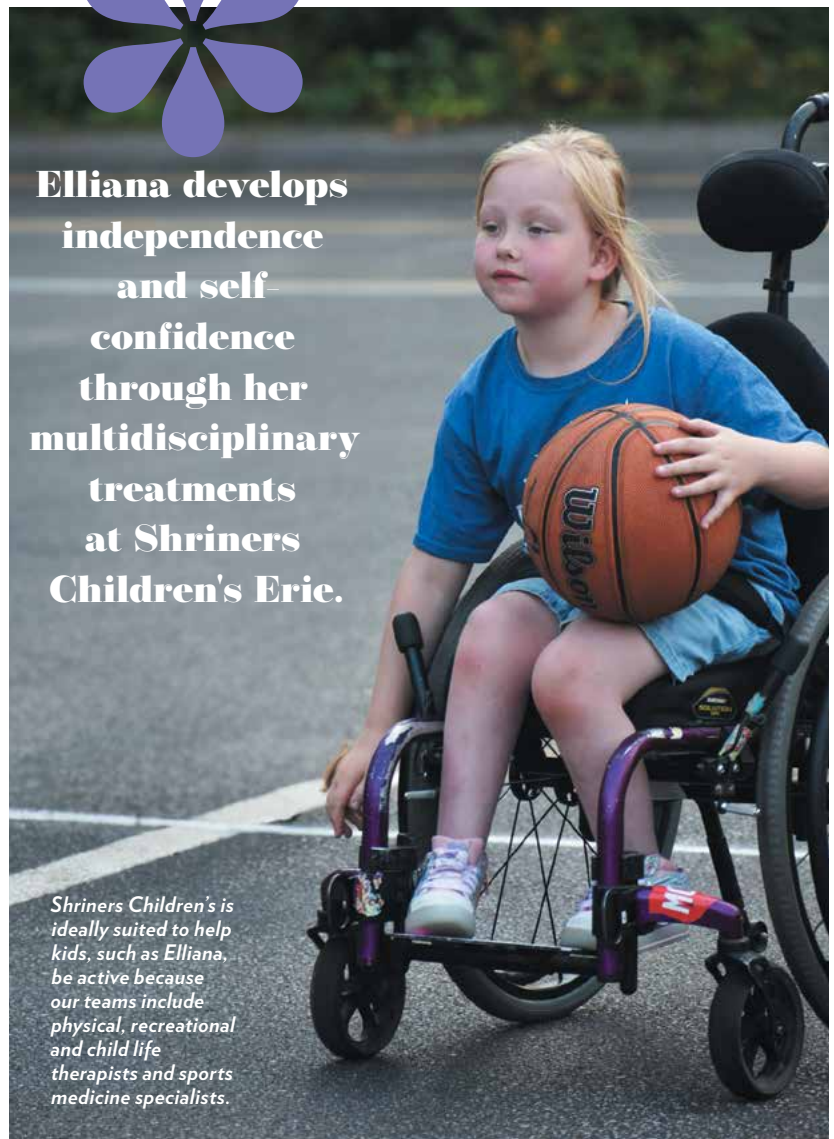
Adaptive sports for spinal conditions

At Shriners Children's Erie, patients with spina bifida are encouraged to participate in adaptive sports. Shriners Children's is ideally suited to help kids be active because our teams include physical, recreational and child life therapists, and sports medicine specialists.

A therapeutic riding program allows children with spinal cord conditions to ride a horse forward and backward to strengthen and stimulate leg muscles, provide a massage and stretch. And it's a whole lot of fun, too.

Patients can also participate in wheelchair basketball and sledge hockey, which help build skills and give kids the chance to enjoy a sport with their peers. Former Shriners Children's Erie sledge hockey players have gone on to the Paralympics and received college scholarships, said Michelle DeRooy, outcomes coordinator at Shriners Children's Erie.

"Adaptive sports programs promote healthy physical activity, strength building, endurance and coordination," says Kristin Maguire, a child life specialist at Shriners Children's Erie. "For patients with spina bifida, adaptive sports improve mobility, reduce muscle weakness and enhance balance, building on the progress made in physical therapy by reinforcing skills in a fun, real-world setting."



Elliana develops independence and self-confidence through her multidisciplinary treatments at Shriners Children's Erie.


Shriners Children's is ideally suited to help kids, such as Elliana, be active because our teams include physical, recreational and child life therapists and sports medicine specialists.

Elliana is a spunky 7-year-old who has been treated for spina bifida at Shriners Children's Erie for four years. The multidisciplinary care and support she receives there have helped her develop independence and self-confidence.

Elliana has received care through the physiatry program, which has also helped connect her with some of the medical center's adaptive sports offerings. This summer, she participated in wheelchair basketball and enjoyed playing a competitive sport. She also participated in snow tubing and is considering joining the sledge hockey team.

"Overall, simply being active, playing a game they love, makes it a fun and fulfilling experience," said Maguire.

Shriners Children's is a place where patients with spina bifida have access to the latest clinical treatments supported by leading research. And it's where our innovative and therapeutic programs give children the chance to thrive. 🧡

 **LEARN MORE** about spina bifida care, scan the QR code.





MJ, born with Crouzon syndrome, has been making great progress after having a major surgery at Shriners Children's Ohio to relieve the pressure in his brain.

Where Treating the Rare Is Commonplace

Shriners Children's surgeons treat craniofacial conditions with innovative surgeries and comprehensive care

"We want families to know we are going to take great care of their child and get them an amazing outcome."

— CHRISTOPHER GORDON, M.D.

"I used to only be able to think of one thing at a time. Now I can think of many things," MJ, 16, told his doctor, Christopher Gordon, M.D., a plastic surgeon at Shriners Children's Ohio.

MJ was born with Crouzon syndrome. He had many of the common characteristics of this craniofacial condition, including wide, bulging eyes, protruding tongue and difficulty walking. The condition is caused by a mutation that causes the skull bones to mature and fuse too quickly, so the brain is compressed and can't grow the way it should.

Dr. Gordon recalled the conversation he had with MJ just a few months after major surgery to relieve the pressure in his

brain. Now that his brain has room to grow, not only is MJ able to “think of many things,” but the teen can walk steadier and even jog.

Crouzon syndrome is one of several conditions caused by a mutation in the Fibroblast Growth Factor Receptor (FGFR), which is involved in neural and skeletal development. Treacher-Collins, Goldenhar, Apert and Crouzon syndromes are some of the most common FGFR disorders.

Dedicated craniofacial care

Thousands of babies are born every year with craniofacial abnormalities ranging from minor cleft palate with or without cleft lip to more complex malformations that involve the teeth, skull, jaw and ears. These can often lead to problems with feeding, hearing and sight, and require a specialized team working toward one goal: the best outcome for the child.

With cleft lip and palate making up the largest percentage of craniofacial conditions a child can face, other anomalies range from uncommon to rare. Many parents struggle to find doctors with the expertise to treat their child.

That’s where Shriners Children’s comes in. Craniofacial surgeons at our hospitals and clinics specialize in treating these rare conditions that many doctors have never even seen.

For Dr. Gordon, helping children born with craniofacial conditions is his life’s work. One of the rarest conditions is Apert syndrome, which typically includes deformities of the skull, face and limbs. Symptoms include a high forehead, underdeveloped upper jaw and wide-set eyes. Children can also have problems with their vision and teeth.



Christopher Gordon, M.D.

“Apert syndrome is something I thought I’d see maybe once in my career, but the word is getting out that

Shriners Children’s has the expertise and resources to care for children with this condition, and Shriners Children’s Ohio is currently treating five children.” To date, craniofacial teams from 13 Shriners Children’s locations across the U.S. have treated, or are currently seeing, patients with this extremely rare condition.

A comprehensive team of specialists

While craniofacial conditions vary, Dr. Gordon is confident that Shriners Children’s multidisciplinary approach creates life-changing outcomes.

“At Shriners Children’s, the children we take care of are treated by a team of specialists,” he said. “We consult with neurosurgeons, speech therapists, dieticians, nurse care managers, and physical and occupational therapists.” Cleft and craniofacial teams across the healthcare system also include pediatric psychologists to support the emotional needs and school experience of patients with craniofacial differences.

“I can’t imagine what it’s like to be a parent [of a kid] with this kind of diagnosis,” Dr. Gordon said. “But we want families to know we are going to take great care of their child and get them an amazing outcome.”



Shriners Children’s Chicago expanded on-site imaging by adding a cone beam CT machine, offering advanced imaging for patients with cleft and craniofacial conditions.

Imaging for precise treatment

Advanced imaging is another hallmark of care for Shriners Children’s patients with cleft and craniofacial conditions. Shriners Children’s Chicago expanded its on-site imaging this year with the addition of a cone beam CT machine (CBCT). The device evaluates a patient’s facial anatomy, particularly the bones and dental structures, providing important data to pediatric plastic surgeons.

“Quality imaging is essential to accurately plan and time surgical procedures,” said David Morris, M.D., medical director of the cleft and craniofacial team at the Chicago hospital.

With the child seated, a rotating arm moves around the patient, and a cone-shaped X-ray beam, which delivers less radiation than traditional CT scanners, provides physicians with a 3D image of the child’s mouth, jaw, airway, neck, teeth, ears, nose and throat. “These images are used to directly plan jaw surgeries and evaluate the outcomes of such surgeries,” Dr. Morris said. >>

In a CBCT, a rotating arm moves around the patient with a low-radiation X-ray beam to produce detailed 3D images.



Kayla before receiving her jaw surgery.



Kayla after receiving her jaw surgery.

A new smile for Kayla

Kayla is an aspiring artist with a great imagination. “Kayla always has ideas,” said her mom, Lilly. “She loves to draw and is a great organizer.”

Kayla, who is deaf, had a noticeable underbite, and as a result, her teeth did not meet correctly.

This made it hard to bite, chew and eat comfortably.

Dr. Morris scheduled Kayla for orthognathic (or jaw) surgery at Shriners Children’s Chicago. Dr. Morris performed surgery to

reposition Kayla’s jaw. Now her teeth and jaws are aligned, and she can focus on building her creative business.

The pair frequently talked about art projects they are working on. The family said the care and the setting surpassed expectations.

“It was incredible, amazing,” said Lilly. “It seemed like when you walked in, everybody already knew who you were.”

Filling the research gap

For children born with craniofacial microsomia, one side of their face is underdeveloped. This causes an asymmetry, with half of the face being smaller — usually the ears, jaw and mouth, and possibly the eyes, cheeks and neck.

Craniofacial microsomia is the second most common craniofacial anomaly after cleft lip and palate. But it is still very rare, occurring in only an estimated 1 in every 3,500 to 5,600 births. As a result, little attention has been given to the causes of this condition. In fact, it has hardly been researched at all.

Chad Purnell, M.D., a pediatric plastic surgeon at Shriners Children’s Chicago, is ready to fill that research gap. With a passion for caring for children with craniofacial disorders, Dr. Purnell and the team of eight plastic surgeons have helped build the Chicago hospital’s reputation for providing successful surgical outcomes for kids with craniofacial microsomia.

Dr. Purnell has teamed up with Shriners Children’s Philadelphia plastic surgeon Eric Chien-Wei



Chad Purnell, M.D.

Liao, M.D., Ph.D., who is also director of craniofacial innovation at Children’s Hospital of Philadelphia, to remedy this. Together, they are in a unique position. They have built reputations for treating craniofacial microsomia, so Shriners Children’s has the patient population to study the genetic causes of the rare condition.

Dr. Purnell and Dr. Liao intend to compare patients’ DNA to that of their parents, looking for potential causes. They hope to compare differences in presentation and DNA to learn about what influences severity and study DNA from each side of the face.

“You can’t treat anything well until you understand it well,” said Dr. Purnell. “Our understanding of this disease process is very limited. We’re hoping this study helps us understand the mechanisms. If we understand the mechanisms, we can better treat it.”

“You can’t treat anything well until you understand it well.”

— CHAD PURNELL, M.D.



SHRINERS CHILDREN'S has the expertise to treat a full range of cleft and craniofacial conditions. For more information, scan the QR code below.



champions IN HEALING

EMPOWERING PATIENTS, FAMILIES & CARE TEAMS

Healing in Resilience

Shriners Children's is exploring the interplay of innate strengths and environmental influences in patient healing

Anna. Lincoln. Dustin. These patients have all shown remarkable resilience in the face of serious medical challenges that have spanned their lives. What gives them the strength to persevere and thrive?

"It's almost a cliché to say, but children are naturally resilient," said Kyle Deane, Ph.D., pediatric psychologist and researcher at Shriners Children's Chicago. "They are more likely to adjust to new realities, even difficult ones. Adapting becomes another part of their growth process."

A child's resilience depends on many factors, however. For some, resilience is an innate strength that drives them from within. For others, resilience is influenced by their environment. Either way, resilience plays a crucial role in the healing process, which is why Dr. Deane is leading a study to better measure and understand it. >>

Dustin, who had both legs amputated below the knee, is an avid athlete and loves anything that brings him outdoors.

Kyle Deane, Ph.D., pediatric psychologist and researcher at Shriners Children's Chicago, helps his patients adjust to new realities of their conditions.



“Resilience can be fostered, which is a huge reason we need this measure. By understanding a patient’s mindset, we can personalize our treatment approach.”

— KYLE DEANE, PH.D.

Measuring resilience

Dr. Deane and his team are developing a measurement tool to assess how young people perceive their disability, including their coping resources, potential responses and likelihood of success.

Given the significant role that parents and caregivers play in rehabilitation and recovery, a parent/caregiver report is also being created.

“Resilience can be fostered, which is a huge reason we need this measure,” said Dr. Deane. “By understanding a patient’s mindset, we can personalize our treatment approach. We do this by helping them reframe negative thoughts, encouraging problem-solving skills and building their confidence in their ability to overcome obstacles.”

The collaborative, multidisciplinary approach at Shriners Children’s is instrumental in fostering resilience. “I see the resilience in our patients amplified because of the supportive environment we create,” said Dr. Deane.

Inspiring and motivating staff

Clinicians are key to fostering resilience in their patients, and those same kids and teens inspire and motivate staff in turn. Working with children who have major health challenges might get heavy. But staff say they often go home uplifted by their patients’ upbeat resilience.



Tiffany Romias, OTR/L, is an occupational therapist at Shriners Children’s Northern California, where she has worked with patients with burns for over 25 years.

When Tiffany started out, she was anxious about working with children. She wasn’t sure she could handle it emotionally. That was doubly true when faced with the prospect of treating kids who had devastating burn injuries.

One of her first patients was 8-year-old Anna, who had burns covering most of her body. As part of her introduction, Tiffany observed Anna’s dressing change, debridement and skin grafting.

After the procedures, Tiffany stayed with Anna as she recuperated. Music was playing, and a popular

dance song came on — one Tiffany particularly liked, and she started to enjoy the beat. Then she noticed that Anna, who was bandaged and lying in bed, having just gone through an extremely difficult treatment, was bouncing slightly, in time with the music. Tiffany realized Anna was trying to dance.

“It was very powerful and still gives me chills when I think or talk about it. Anna’s body was so damaged, but her spirit was so strong and intact,” said Tiffany. “That was a huge, pivotal moment for me to understand the power of her strength and resilience despite her challenges.”

Lincoln’s determination

“Like tiny seeds with amazing power to push through the toughest ground and become mighty trees, Lincoln holds innate reserves of unimaginable strength,” said Penny Guild, MSSA, LSW, a social worker at Shriners Children’s Erie.

Lincoln was just a week old when he swallowed two button batteries. When a battery gets stuck in the throat or stomach, it can be fatal. A chemical reaction begins that can cause burns and tissue damage. For Lincoln, the batteries damaged his esophagus, trachea, stomach and kidneys and caused injury to all four of his limbs.

Now 13, Lincoln has been a patient at Shriners Children’s Erie since he was a baby. It has not been an easy path for this young teen. He has had surgeries and many therapies and received dietary and nutrition services. Yet, through it all, he has displayed incredible strength and positivity.

“Once you decide what it is you want, just figure it out. Even if you are told you physically can’t, you can,” said Lincoln. “There’s always a way.”

Because of significant damage to all four of his limbs, Shriners Children’s Pediatric Orthotics and Prosthetic Services (POPS) fitted Lincoln with a prosthetic leg and an ankle foot orthosis,

a medical device that helps stabilize and control the foot and ankle. Lincoln's fingers were all amputated at the first knuckle, and when Lincoln was 8, surgeons performed a below-knee amputation on his left leg.

Prosthetist Hannah Clark, CPO, said that Lincoln shows tremendous determination to get the most benefit from his assistive devices. With hard work, his dexterity improved, so he can put his devices on independently, and he has become proficient in using them.

"Despite all he has been through and the effort he has to put in to do daily tasks, Lincoln always has a great attitude and refreshing sense of humor," said Hannah.

Physical and occupational therapy are also a large part of Lincoln's treatment. Physical therapist Laurie Hudson, PT, is another care team member who has seen how his positive outlook has been an important factor in his health journey.

"Lincoln is the poster guy for resilience. He continues to seek out more exercises and activities to become as independent as possible," said Laurie. "He is willing to work hard to achieve a positive outcome and doesn't give up just because it's hard.

With that attitude, I believe he'll accomplish his dreams and goals."



Mariana Pineda, Ph.D.

Facing treatments with optimism

Shriners Children's Mexico psychologist Mariana Pineda, Ph.D., believes resilience can be fostered by helping patients understand and cope with their medical challenges. "Compassionate healthcare environments like Shriners Children's help patients and their families

manage their experiences," she said. "We encounter patients who not only face their treatment with optimism, but have also grown stronger from the experience, developing a sense of self-efficacy."

To help develop these skills, Dr. Pineda implemented the Pre-Surgical Preparation Program, which familiarizes children with the surgical process.

Her team designed a surgical simulator using medical materials to recreate the experience in a playful manner. Informative videos, featuring doctors and psychologists who walk through the surgical process, teach patients coping skills such as breathing and mindfulness.

The program familiarizes patients with expected emotions, builds coping skills and fosters mental strength in managing their surgeries and treatment journeys.

Families play an important role

How a family responds to a child's diagnosis plays a crucial role. Dr. Deane said that often, in the medical world, clinicians are at risk of focusing solely on the individual, but family dynamics and caregiver involvement are extremely important. "When families



Today, Dustin works as a volunteer firefighter and EMT.

are well-supported, it positively impacts the child's ability to cope and heal," he said. "That's why getting both the child and parent perspective on our new tools will help."

Dr. Pineda agrees. "Parents can nurture resilience by serving as role models and using learning strategies to recognize and manage their emotions. When a patient hears validation and recognition from their parents or medical staff, it strengthens their identity, self-esteem and resilience," she said.

Dustin's unyielding spirit

Dustin was born with an extreme clubfoot on one leg and severe bone deformities on the other, and his hand was webbed like a duck's foot. He underwent numerous surgeries at Shriners Children's St. Louis shortly after he was born to correct his hand and clubfoot and amputate his other leg below his knee. When he was 18, Dustin decided to have another amputation to remove his club foot, as it no longer supported him.

Orthopedic surgeon Mark Miller, M.D., first met Dustin in 2014. He has been impressed by Dustin's resilience in overcoming the challenges he has faced his entire life, and since 2018, wearing prosthetics on both of his legs.

"Dustin has an amazing outlook and perspective," said Dr. Miller. "He is an inspiration to me and has served as a guide and friend for several of my patients and families who are faced with the tough decision of continuing reconstructive options versus maximizing function with an amputation."

Despite these challenges, Dustin never lets his physical differences hold him back. Throughout his life, he has been an avid athlete and loves anything that brings him outdoors — hunting, fishing, hiking and archery.

Now 24, when Dustin is not headed outdoors for his next adventure, he works as a volunteer firefighter and EMT. He is now on a mission to climb wildfire lookout towers.

"Stairs are usually an amputee's nightmare, which is why I climb towers," said Dustin. With his physical strength fueled by his mental toughness and resilience, Dustin shows others that if he can do it, anyone can. 🙌



READ MORE about our inspiring patients in **Leaders in Care** at myleadersincare.com.

The Magic of Galveston's Mardi Gras

Patients, staff and the community come together for this island tradition

Mardi Gras in Galveston is a tradition that goes back to 1867 when a masked ball celebrating the holiday was first held in the city. By 1871, it became a citywide carnival, and it grew over the years to eventually become what is now: a two-week-long festival featuring an abundance of celebrations, concerts and colorful parades. Galveston's event is now the third-largest Mardi Gras celebration in the United States, just behind New Orleans and St. Louis. More than 250,000 visitors come to the island every year during the two weeks preceding Lent.

Lining streets with joy

A special highlight of Galveston's Mardi Gras is the Shriners Children's and Sunshine Kids Parade, which is held on the last Sunday afternoon of the celebration. The parade route follows the shape of a huge rectangle, which wraps around several city blocks in the downtown area of Galveston. The central part of the route is on The Strand, Galveston's main street and center of commerce.

Some parade attendees dress in clown costumes to walk along the route.

Tiny cars, mini-bikes, motorcycles, go-carts and old fire engines are driven by Shriners fraternity members who come from across Texas to join the fun.



From left to right: Xavi, Nathan and Grey show their collections of beads.

During the parade, patients and staff from Shriners Children's Texas ride on floats and throw out beads and goodies to the crowds of families lining the streets. Tiny cars, mini-bikes, motorcycles, go-carts and old fire engines are driven by Shriners fraternity members who come from across Texas to join the fun. Some dress in funny clown costumes and walk along the route, while others ride on elaborate floats decorated in colorful Mardi Gras themes. Shriners Children's mascot, Fezzy, usually makes an appearance, too.

"This is a special day for our patients and for the Shriners."

— ANGEL MARTINEZ, RN

Building community through tradition

The parade is a great way for Shriners, patients, families and staff to come together for a fun and exciting celebration each year. For patients, it's a special time to get out into the community. The kids are the center of attention while they ride the festive floats and are the true stars of the parade. For Shriners, it's a great bonding time for the fraternity when their fellow members from across the state come together for a common purpose. After the parade, you'll find many at a huge cookout held a few blocks away at El Mina Shriners, the local Shriners chapter in Galveston.

Angel Martinez, RN a nurse at Shriners Children's Texas, has helped coordinate the parade participation for patients, staff and Shriners for many years.

"This is a special day for our patients and for the Shriners," Martinez said. "It's fantastic that Shriners Children's Texas plays a central part in one of the biggest events in Galveston, and it's great to see so many Shriners come to participate. Every year, it keeps getting bigger and better!"

The 2025 Galveston Mardi Gras Shriners Children's and Sunshine Kids Parade will take place on Sunday, March 2, at noon. 🎉



systemwide STRENGTH

DEDICATED TO CARING FOR MORE KIDS IN MORE PLACES

Shriners Children's Patients Excel at the **Paralympic Games**



Former and current patients show the world what they're capable of, redefining the concept of ability



READ MORE about Shriners Children's patients who have competed in the Paralympics by scanning the QR code.

Current and former Shriners Children's patients showcased their incredible talent and determination on the world stage at the 2024 Paralympic Games in Paris. The athletes, who participated in events ranging from para canoeing and wheelchair basketball to shot put and para swimming, embodied the organization's mission of helping children overcome physical challenges. They are a huge source of inspiration for our current patients, as they understand better than anyone the challenges and adversity that must be overcome to reach great heights. >>



TATYANA MCFADDEN: WHEELCHAIR RACING

Treated at Shriners Children's Philadelphia

Tatyana McFadden has 22 Paralympic medals, including eight gold, dating back to Athens in 2004. Paris marked her seventh Paralympic Games. She won silver in the women's 100m T54 and won a bronze medal in the Mixed 4x100 Universal Relay. Tatyana was born with spina bifida and lived her first six years in Russia. When she came to the U.S., Tatyana had surgeries to align her legs at Shriners Children's Philadelphia. "Shriners Children's has a footprint that is worldwide, and I'm part of it. I believe we could run our own little country," she said.

NOELLE MALKAMAKI: SHOT PUT

Treated at Shriners Children's St. Louis

In her Paralympic Games debut, Noelle Malkamaki won her first gold medal, broke her own world record on two of her three throws, and became the first to throw over 14m in women's shot put F46. Noelle's athletic career spans multiple sports, including track and field and volleyball. She was born with amniotic band syndrome, a congenital birth defect that prevented her right hand from developing. Care at Shriners Children's St. Louis allowed her to pursue her athletic dreams. "There was comfort knowing that I didn't have to have any boundaries because Shriners Children's could help figure something out with prosthetics," she said.



HUNTER WOODHALL: PARA TRACK

Treated at Shriners Children's Salt Lake City and Florida

Hunter Woodhall, a double-amputee sprinter, surged down the final stretch to overtake the defending champion and capture gold in the men's 400-meter T62 event. He has a total of five medals: one gold, one silver and three bronze. Born with fibular hemimelia, Hunter underwent bilateral below-the-knee amputations at Shriners Children's Salt Lake City at 11 months. The hospital's team enabled Hunter to pursue his athletic dreams. "Anytime I asked for a new prosthetic for whatever sport I was playing, they built one for me," he said. "They weren't doing this for the Hunter Woodhall people know today. They were doing that for a kid who just wanted to try something new." His wife, Tara Davis-Woodhall, is a 2024 Olympic gold medalist in the long jump, making them a dynamic duo in track and field.

ZION REDINGTON: WHEELCHAIR RUGBY **Treated at Shriners Children's Lexington**

This was Zion Redington's first Paralympics, and at 18, he was the youngest player on the wheelchair rugby team in Paris, bringing home a silver medal. Zion was named to the roster at 17, making him the youngest player in history to be named to the U.S. wheelchair rugby Paralympic team. Born in China with ectrodactyly, a condition causing the absence of central digits on his hands and feet, Zion had his feet amputated at age 6 to improve mobility. But that never slowed him down. By age 9, he was already trying various adaptive sports, and by 15, he had made his national team debut in wheelchair rugby. "Shriners Children's gave me the opportunity to see there's a whole new world for Zion as an amputee," said his mom, Heather.



BETHANY ZUMMO: SITTING VOLLEYBALL **Treated at Shriners Children's Northern California**

Bethany Zummo won gold in Paris, making her a three-time gold medalist with the sitting volleyball team. The team took gold for the third Paralympics in a row, making it a historic three-peat. Bethany was born with two congenital disorders and had her right foot amputated at Shriners Children's Northern California when she was 2. She grew up regularly being fitted for her prosthetics at the hospital. "The best day of the week was being able to go to Shriners Children's for an appointment. I'm so thankful for my doctors," she said.

BRIAN BELL: WHEELCHAIR BASKETBALL **Treated at Shriners Children's Greenville**

Former Shriners Children's Greenville patient Brian Bell discovered his love for wheelchair basketball when he was 12, and the sport became his passion. Shriners Children's helped lead him to his passion after he experienced a train accident two years prior, which resulted in him losing his right leg. "Shriners Children's Greenville did everything and beyond to help me and keep me accountable, making sure I did all my rehab drills and exercises. Shriners Children's is a great hospital and organization," said Brian. He won gold in Paris, making him a three-time Paralympic gold medalist.



Champions in life

Shriners Children's takes immense pride in having played a part in the journeys of all the accomplished patients and former patients who competed in Paris. Whether they won a medal or not, they are all champions in the eyes of the Shriners Children's community. 🏆



From Small Town to World Stage

Matt Aldridge's inspiring journey from patient to Paralympic athlete

Imagine this: You're a small-town boy, stepping into the blinding light of the Olympic Stadium, surrounded by 90,000 cheering fans, the iconic chant "USA!" ringing in your ears. This was the surreal reality in 2004 for Matt Aldridge, Paralympic powerlifter and former Shriners Children's Greenville patient.

Matt Aldridge with his children, who are all Shriners Children's patients.

Diagnosed with tibial aplasia-ectrodactyly syndrome, Matt underwent double amputation of his lower legs at 15 months, which allowed him to walk with prosthetics. With the support of Shriners Children's, he learned to embrace his differences and push beyond limits. His care team instilled a can-do attitude that would shape his life.

In middle school, a strength test ignited Matt's competitive fire. He discovered weightlifting and leveraged his unique hand shape to his advantage.

"With my condition I have larger than average palms with relatively short fingers. This means my hands are a perfect fit for the weight bar, and I used that to my advantage," said Matt.

Before long, he was shattering records and catching the eye of Team USA coaches.

By 2004, Matt stood alongside the world's elite weightlifters in the Paralympic Games. This country boy had become a global athlete, embodying the Olympic motto: "Faster, Higher, Stronger."

Today, Matt is the father of three current Shriners Children's patients — all diagnosed with the same genetic condition that led his parents to seek care for their son 40 years ago. With a health and physical education degree, the Paralympian also encourages children at the YMCA where he works. His journey is a reminder that with the right support, we can overcome any obstacle and reach unimaginable heights. 🏆

Little Champions

Patients at Shriners Children's Chicago embrace the Paralympic spirit

Forget watching the games — Shriners Children's Chicago patients got in on the action. Festivities started with a "torch run," and patients rolled, walked or cruised around the hospital on opening day. The final "runner" arrived in time for the Paris opening ceremonies. Talk about a star-spangled entrance: Ezra, a 17-year-old patient with scoliosis and violin virtuoso, played the national anthem.

But the excitement didn't stop there. Over the next 12 days, recreational therapists showcased adaptive sports in the hospital mall. From blind football (American soccer for patients with visual impairments) and para badminton to sitting volleyball and wheelchair basketball, patients and staff embraced the Paralympic spirit.

As visitors gathered to watch and play, therapists asked a powerful question: What lights your flame? Answers filled a giant cutout torch, a glowing reminder that these kids are proof that with spirit and support, every child can shine. 🏆



Patients moved around the hospital for a torch run to kick off their own Paralympics.



Tyshaun caps off the "torch run" to start the Paralympics.



Kaden participates in Paralympic activities at Shriners Children's Chicago.

The Healing Power of Giving Back

Your donations help children at Shriners Children's gain independence and conquer challenges

Donors help children like Preston, who was diagnosed with a complex clubfoot and unable to walk. After multiple surgeries and extensive physical therapy, Preston is now not only walking but competing as a gymnast, specializing in the pommel horse.

Your gift can help provide a therapeutic session to help a child develop strength and pursue their dreams.

That's because our pediatric rehabilitation and therapeutic services support each patient's physical, developmental and emotional needs. The focus is on long-term independence. Shriners Children's staff teach patients special exercises, occupational skills like getting dressed and coping techniques to create better lifelong outcomes. Our team makes it fun by using pets, music and more.

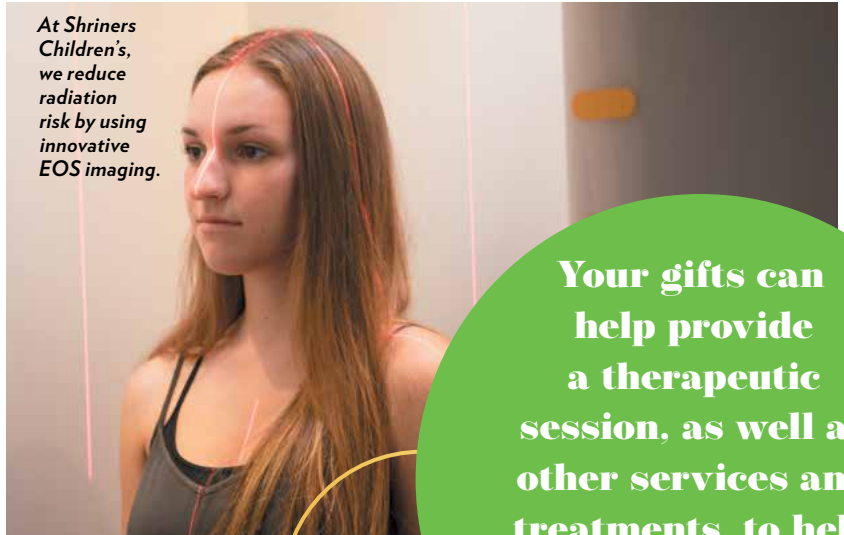
Innovative care for patients

Providing immediate pain relief to patients with burn injuries during assessment is critical. Aside from visual assessment, the only accurate way to assess burns has been through often painful biopsies — until now.

A Shriners Children's research team has found that a handheld, pain-free device that uses a light source, the Resonance Raman Spectroscopy, quickly and accurately produces burn assessment results. This is just one example of how Shriners Children's uses leading-edge methods in pain management to help kids heal.

Your donation can help support research projects such as this one — making Shriners Children's a leader in providing exceptional, innovative care for patients with burns.

At Shriners Children's, we reduce radiation risk by using innovative EOS imaging.



Your gifts can help provide a therapeutic session, as well as other services and treatments, to help a child develop strength and pursue their dreams.

Safer X-rays

X-rays expose children to radiation in low doses, but at Shriners Children's, we take additional steps to reduce this exposure. We use EOS imaging systems that provide front and side images while limiting the X-ray dose absorbed by the patient who is either sitting or standing.

EOS offers a number of advantages over more traditional X-ray units, including fast, stress-free, low-dose radiation exams. It's ideal for children with conditions that require multiple X-rays. Studies have shown that using low-dose EOS imaging can reduce the radiation dose by 55%, without compromising image quality.

With these consistent, high-quality images, EOS can deliver more precise measurements, in addition to providing 2D and 3D views of a child's bone structure. The EOS images can give our physicians a clearer picture of a problem and its complexities, which allows them to deliver a more accurate diagnosis and create a more personalized treatment plan.

Your gift helps provide this technology to reduce this risk for Shriners Children's patients by providing low-radiation EOS X-rays before and after treatment.

Providing mobility and independence

Shriners Children's offers adaptive bicycles that give kids more than hours of fun — they help develop motor and cognitive skills and increase self-esteem, physical strength and independence.

Since every child is unique, donations are needed to ensure each bike is built to exact specifications with easy-to-steer handlebars, hand brakes, pedal straps, movable trunk supports, baskets, adjustable seats and a bright orange flag for added safety.

Gifts to Shriners Children's help provide adaptive bicycle frames to give children mobility and independence. 🚲



Shriners Children's patients are able to receive devices such as adaptable bicycle frames, which unlock a world of mobility and independence, thanks to gifts from generous donors.

Charitable Gift Annuity Provides Opportunity to Give Back While Making Income



Lucia made her first contribution more than two decades ago and continues to give today.

When asked why she supports Shriners Children’s, Lucia recalls a specific memory from years ago. She and her mother were sitting in church alongside a little girl and her father who had survived a devastating car crash while vacationing in Spain. The accident had left them both with burns all over their bodies. A little boy sitting behind them

caught a glimpse of the girl and recoiled in shock, commenting on her appearance to his mother.

Lucia said that moment affected her deeply.

She felt called to find a way to help young children who had been through similar accidents. Through a friend, she learned about Shriners Children’s. She toured a Shriners Children’s facility and met patients, noting the activities and resources tailored to ensure that children have a positive healthcare experience. Lucia made her first contribution more than two decades ago and continues to give, now using charitable gift annuities (CGAs) and charitable remainder unitrusts (CRUTS) to support our healthcare system.

“It’s important to me that the majority of the money I donate goes directly to the kids,” shared Lucia. 🙏

Charitable Gift Annuity Rate Chart

ONE LIFE		TWO LIVES	
AGE	RATE	AGE	RATE
60	5.2%	60/65	4.8%
65	5.7%	65/70	5.2%
70	6.3%	70/75	5.8%
75	7.0%	75/80	6.5%
80	8.1%	80/85	7.3%
85	9.1%	85/90	8.7%
90+	10.1%	90/95+	9.9%

FOR MORE INFORMATION
on supporting Shriners Children’s through a planned gift, please contact the Planned and Major Gift office at (813) 367-2241 or by email at plannedgiving@shrinenet.org.

Sharing Hope Through a Gift in His Will

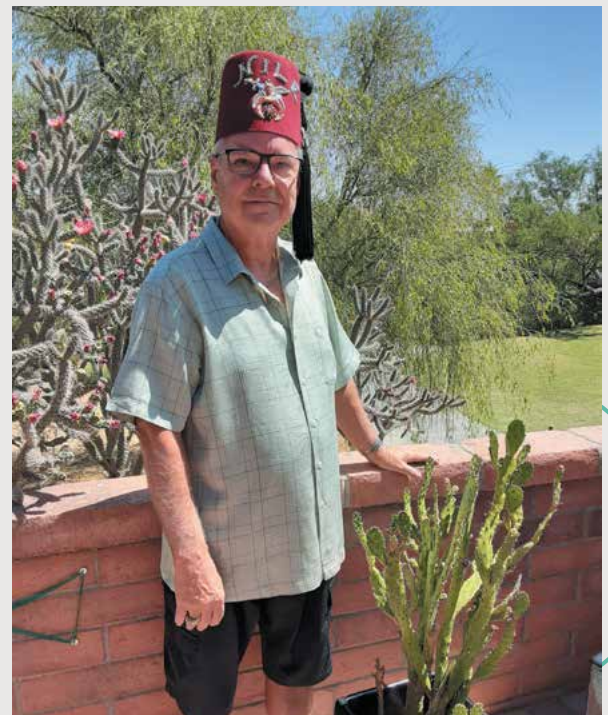
In 2017, Billy learned that his great-nephew, Drake, was coping with a rare orthopedic condition. The 2-year-old’s collarbone was fused with his shoulder blade, causing him to lean to one side as he grew.

“My niece didn’t have the foggiest idea that I was a Shriner,” said Billy, a dedicated fraternity member for 48 years. Thankfully, not only was he able to tell her about Shriners Children’s, but he was able to accompany her to Portland for her son’s successful corrective surgery.

“I was so impressed by the care Drake received,” Billy recalled. “Everything from the whimsical Mickey Mouse wallpaper to the attentive nurse who went overboard to make everyone feel comfortable.”

That experience inspired Billy to name Shriners Children’s as a beneficiary of his estate through the endowment fund. With gifts like this, a percentage of the interest accrued is reinvested into the principal, and as the endowment continues to grow, more funds benefit more children. Today, Billy is an enthusiastic member of the Dream Makers Legacy Society.

“Children are welcomed into this amazing, caring environment where their family and parents don’t have to worry about medical expenses,” Billy observed. “The thought of giving is such a reward in itself, and the best part is that there is no end to this gift — it will go on and on.” 🙏



Billy, a donor and Shriner, encouraged his niece to take her son to Shriners Children’s after learning he had a rare orthopedic condition.



Shriners
Children's™



GOLF FOR **AMAZING CARE**

Turn your love for golf into a powerful fundraiser with Shriners Children's™.

By organizing a golf tournament, you can make an impact for children in need of life-changing medical care. Whether you're a seasoned golfer or just passionate about helping others, visit our website, golfforamazingcare.org, or scan the QR code below to get started.



CREATING SMILES AND SPECIAL MOMENTS

NAME: JOHN

ROLE: ENVIRONMENTAL SERVICES

LOCATION: SHRINERS CHILDREN'S CHICAGO



“It was such a small gesture but made a world of difference ... this is what separates Shriners Children’s from so many other hospitals.” –Aubre.

It’s not just doctors, nurses and therapists who make a big impact on our patients. John, who has worked at Shriners Children’s Chicago for eight years, is a perfect example of someone who is dedicated to providing positive experiences for patients. John works in environmental services (EVS), the specially trained team members who clean patient rooms and common areas in our healthcare facilities. He and the Chicago EVS team are regularly mentioned in patient surveys and on social media for knowing patients’ names and being so friendly.

John received recognition for going above and beyond to help motivate a little boy named Owen try a new sports wheelchair. His mother, Aubre, praised John on the hospital’s Instagram account @shrinerschicago.

“After therapy today, one of the recreational therapists volunteered to help Owen try out one of the athletic wheelchairs. We were trying to get him to chase us and play, and one of the employees walked by and jumped in to help,” Aubre wrote. “Owen loved it and was having so much fun.”

Mom captured the moment on video. Owen can be heard playfully calling, “I’m going to get you, John!”

A girl named Bella, who was at Shriners Children’s Chicago for scoliosis care, is another patient who knows that John is a special member of the team. She made a drawing to thank him after he formed a friendship with the family. John kept the drawing taped to his cleaning cart for months.

“The custodial staff took the time to speak to us and ask how our child was doing,” shared another parent on their post-care survey. “An overwhelming and stressful experience was made much easier by the staff at the hospital.”

SHC-026

Cementing Hope

How a creative family business is giving back to Shriners Children's Chicago

Bella and her sisters found a fun and creative way to keep busy when the pandemic kept them, and other school-aged children around the world, at home for months on end. These fifth- and eighth-graders started making paintable figures out of cement. With their dad's help, the girls expanded to include beautifully crafted garden statues. These young entrepreneurs even turned it into a business.



This past summer the girls decided to give back in a concrete way to Shriners Children's Chicago, where Bella has been a patient since she was 5. They delivered ten statues for the hospital's patient gardens to express their gratitude for Bella's orthopedic care related to cerebral palsy (CP). Her physician, Kelsey Davidson, M.D., also received a custom Shriners Children's gnome.

The family's relationship with Shriners Children's was set in stone, so to speak, when their dad's benefits plan rejected coverage for Bella at another hospital, calling her CP a developmental condition. Their physician referred them to Shriners Children's Chicago, and the family is very grateful for the amazing care provided regardless of their insurance status.

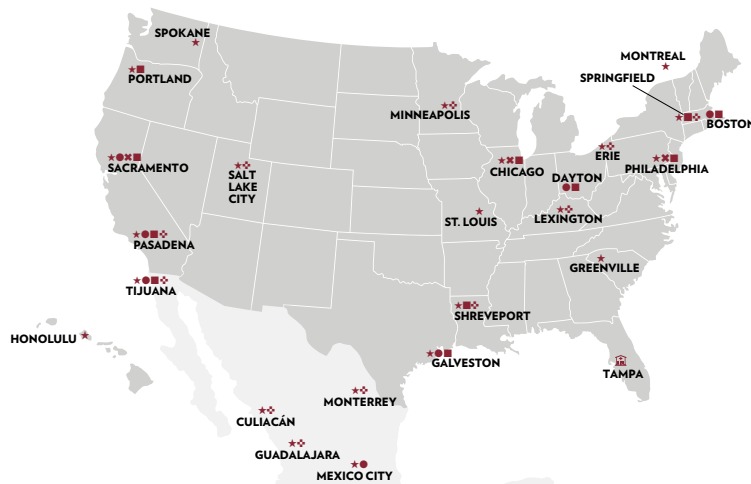


From left to right: Bella, 10, and her sisters Alyssa and Samantha, 13, sit in the garden they've helped make beautiful.

Dr. Davidson has treated Bella, now 10, since 2019. Bella has received multiple leg braces and a tendon lengthening surgery to help her walk more easily.

The sisters keep on giving. At the Chicago Abilities Expo, an event that features products, workshops and adaptive activities for individuals with disabilities, the girls donated paintable figures to all the kids attending. When the event organizer suggested a donation jar, Bella took it a step further. "We're donating 50% of what we make and giving it to Shriners Children's at their booth," she told her dad. At the end of the day, the girls delivered \$80 to the Chicago staff, once again happy to give back to the hospital that has helped Bella thrive.

LOCATIONS



- ★ Orthopedics
- Burn care
- ✕ Spinal cord injury
- Cleft lip and palate
- ⊕ Outpatient care only; necessary inpatient care provided at an affiliated facility
- 🏠 Shriners Children's and Shriners International's Headquarters